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Through a Culturally Targeted Print Intervention

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14. ABSTRACT: Prostate cancer (PCa) incidence and mortality is higher among African American (AA) men compared to all other groups. There is compelling evidence that higher mortality is due to the greater likelihood of AA men to be diagnosed with advanced-stage PCa. PCa screening, specifically prostate-specific antigen test (PSA) and digital rectal exam (DRE), has been shown to increase early-stage diagnoses. Although several organizations recommend annual PCa screening starting at age 45 for AA men, screening among AA men is low. Indeed, interventions to increase screening and the early detection of PCa among AA men are critical. Although culturally targeted health interventions have been found to be effective there are no interventions that have systematically addressed culturally relevant factors in PCa screening among AA men. The primary aim of the proposed study is to develop and evaluate the impact of a culturally targeted (CT) print intervention on PCa screening participation among AA 410 men through a randomized controlled trial. The proposed research also seeks to investigate the mediational pathways (i.e., mechanisms) through which the culturally targeted print intervention impacts screening participation.					
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## Table of Contents

Cover.....	
SF 298.....	2
Table of Contents.....	3
Introduction.....	4
Body.....	5
Key Research Accomplishments.....	5
Reportable Outcomes.....	5
Conclusions.....	5
References.....	5
Appendices.....	7

## INTRODUCTION

Prostate cancer (PCa) is the leading cause of cancer among American men and African American (AA) men carry a disproportionate amount of this burden. PCa incidence and mortality is 60% and 123% higher, respectively, than that of white men (1;2). It has been proposed the higher mortality rate is due to the possibility that PCa has unique disease characteristics in AA men (3). However, there is compelling evidence that higher mortality is due to higher likelihood of advanced-stage diagnosis (4;5) as AA men are more likely to be diagnosed with PCa at a more advanced stage compared to whites (2). A 2003 report on PCa trends from 1969-1999 (6) revealed that widespread PCa screening - specifically the prostate-specific antigen test (PSA) - led to a marked increase in early-stage diagnoses in the 1980s and was followed by a decline advanced-stage mortality. In other words, as early-stage diagnoses increased, advanced-stage diagnoses decreased, thereby decreasing deaths from advanced-stage disease. In light of the higher rates of advanced-stage diagnosis and mortality among AA men, the promotion of early detection of PCa through screening has the potential to reduce significant ethnic disparities in cancer. The majority of organizations agree that the benefit of routine screening may be larger among AA men and half recommend that AA men should be offered annual screening in their 40's (7;8). Unfortunately, there is considerable evidence that AA men are less likely to be screened compared to White men (9-13). There are relatively few PCa screening interventions that focus on AA men and these have resulted in only modest increases in screening. One explanation may be that none have systematically addressed culturally relevant factors in PCa screening, even though culturally targeted (CT) health interventions are reported to be more effective than generic interventions. Therefore, it is important to investigate whether a CT intervention is more effective in increasing PCa screening than a generic intervention. The importance of culturally relevant factors is supported by social identity theory (SIT), which defines social identity as that part of the one's self-concept that derives from their knowledge and evaluation of membership in a social group (14). This study is also guided in the Theory of Planned Behavior (TPB) (15). TPB posits that behavior is predicted by several variables: intention to engage in a behavior; attitudes (one's evaluation of a behavior); perceived group norms (one's perception of reference group desires that the individual participate in the behavior); and perceived behavioral control (one's appraisal of his or her ability to engage in the behavior). Studies have reported that attitudes, norms, and behavioral control were significant predictors of intention to participate in cancer screening (16) and intention was the strongest predictor of actual participation (17). This is consistent with findings that intention to participate in PCa screening significantly predicted screening participation (18).

In the current research, we expect that the association between the CT intervention and adherence to PCa screening guidelines will be mediated by screening intention, attitudes, perceived group norms and behavioral control over screening, as well as PCa knowledge and perceived risk. In other words, individuals who will be most likely to participate in screening following an intervention are those who experience substantive changes in these variables. For reasons addressed by social identity theory, it is also proposed here that a CT intervention will lead to greater changes in these mediating variables and therefore have a greater impact on screening participation. The identification of culturally relevant factors that may be addressed in a PCa screening intervention is essential. Additionally the study will examine three important culturally relevant factors to include in a PCa screening intervention, medical mistrust, and collectivism.

**HYPOTHESES :** The objectives of the proposed research are to: 1) develop and evaluate the impact of a culturally targeted (CT) print intervention on prostate cancer (PCa) screening participation in a sample of 410 AA men through a randomized controlled trial, and 2) to investigate the mediational pathways (i.e., mechanisms) through which the culturally targeted print intervention impacts screening participation. Hypothesis 1: Participants in the CT condition will report greater PCa screening participation following that intervention compared to men in the generic intervention condition. Hypothesis 2: Men in the CT intervention will report greater changes in screening intention, attitudes, group norms, behavioral control, PCa knowledge and perceived PCa risk, and these variables will mediate the impact of the CT intervention on screening participation. Exploratory Hypothesis 1: Culturally relevant variables will moderate the impact of the CT intervention such that men with stronger ethnic identity, medical mistrust, spiritual faith, and collectivist attitudes will benefit more from the culturally targeted intervention.

## **BODY**

In the past year, we have completed several tasks outlined in the original Statement of Work for Months 2-11 based on the current protocol.

*Development of culturally targeted brochure:* The PI collaborated with co-investigators Hall and Valdimarsdottir and consultant Kreuter to develop content for the culturally targeted brochure. In the original statement of work, we stated that we would also develop content for the standard brochure. However, the research team decided to use a brochure already used in the field: a brochure developed by the American Urological Association (AUA) titled, "Prostate Cancer Awareness for Men" (see Appendix 1). The AUA was contacted for permission to use their brochure and its use for research purposes was enthusiastically supported.

*Work with graphic designer to design intervention newsletters:* Using Microsoft Publisher, the research team designed the culturally targeted newsletter (see Appendix 2).

*Refinement of assessment strategies:* The PI collaborated with Drs. Hall, Valdimarsdottir and Kreuter to finalize an assessment battery (see Appendix 3). These revised measures are currently under review by the DOD's and Mount Sinai's IRB.

*Coordination of focus groups:* The PI has been working with Dr. Hall to identify men for the focus group component of the study (see Appendix 4 for letter to prospective participants). We have also completed the guide to be used by a moderator during the focus groups (see Appendix 5).

## **KEY RESEARCH ACCOMPLISHMENTS**

1. Development of culturally targeted brochure
2. Work with graphic designer to design intervention newsletters
3. Refinement of assessment strategies
4. Start of coordination of focus groups and completion of moderator guides for focus groups

## **REPORTABLE OUTCOMES**

We received DOD IRB approval in September 2005. Although the study is in progress, there are no reportable outcomes based on the current protocol at this time.

## **CONCLUSIONS**

We are poised to complete tasks related to completion of the focus group component of the study and have been communicating with lodge leadership on issues of recruitment for the randomized controlled trial (the current protocol states that lodges will serve as recruitment sites).

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## **APPENDICES:**

The following appendices are attached:

- Appendix 1: Standard prostate cancer brochure
- Appendix 2: Draft of culturally targeted prostate cancer brochure
- Appendix 3: Randomized control trial questionnaire
- Appendix 4: Letter from Dr. Hall to recruit participants for focus group study
- Appendix 5: 3 Focus group questionnaires

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## **Appendix 1: Standard prostate cancer brochure**





# Prostate Cancer Awareness for Men



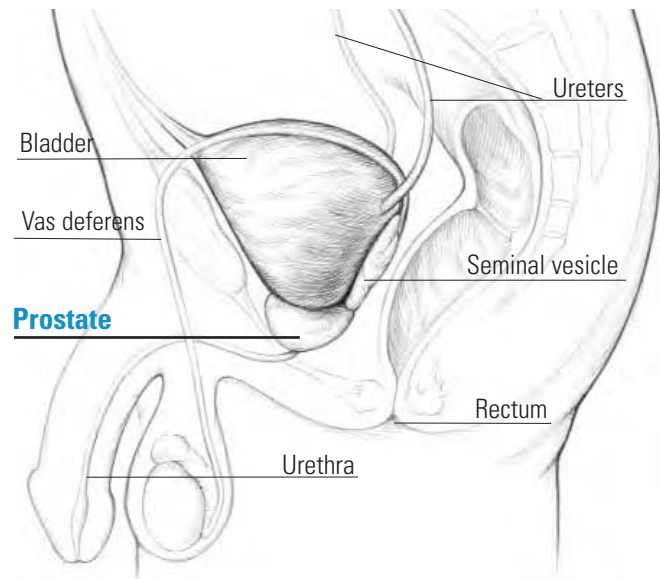
A doctor's guide for patients  
developed by the American  
Urological Association, Inc.®

Based on the PSA  
Best Practice Policy



## WHAT IS THE PROSTATE?

The prostate gland is part of the male reproductive system. It is about the same size and shape as a walnut and weighs only about an ounce. As pictured in the diagram, the prostate is located below the bladder and in front of the rectum. The prostate surrounds a tube called the urethra that carries urine from the bladder out through the penis. The main function of the prostate is to produce fluid for semen.



## WHAT IS PROSTATE CANCER?

There are many different types of cancer. In fact, cancer is really a group of diseases that affects different cells in the body. Prostate cancer is a disease that affects the cells of the prostate. Normally, cells grow and divide in an orderly way. This is how the body grows and stays healthy. Sometimes this normal process of cell growth can go wrong. If the cells continue to divide when they're not supposed to, they can form a tumor. Cancerous prostate tumors can block the flow of urine and, if untreated, can spread to other parts of the body.



## PROSTATE CANCER: THE FACTS

Prostate cancer is one of the most common forms of cancer in men. It is the second leading cause of male cancer deaths in the United States. Most men with prostate cancer do not die from this disease. Yet, prostate cancer still accounts for more than 30,000 American deaths each year.

- **Growth rates for this type of cancer can vary.** Studies have shown that prostate tumors grow at different rates in different people. While some cancers advance rapidly, others grow slowly over many years.
- **The majority of newly diagnosed prostate cancers are localized.** (The tumor growth has not spread beyond the prostate gland.) Given enough time and left untreated, some of these localized tumors can grow in size and spread outside the prostate.
- **Localized prostate cancer usually causes no symptoms.** Prostate cancer usually causes no symptoms until it has spread beyond the prostate. This is one reason why early detection may be important.
- **When the cancer spreads beyond the prostate, it becomes more difficult to manage and the risk of death rises.** It is important to diagnose prostate tumors at an early stage so that they can be watched and treated before the cancer spreads. Although all prostate cancer is potentially life-threatening, in many cases the disease can be cured.

Once prostate cancer is detected, a number of treatment options may be recommended. Each type of treatment poses its own risks and benefits. This booklet is designed to provide information on the early detection and treatment of prostate cancer so that patients, along with their physicians, can make informed, individual decisions about the management of this disease.



## PROSTATE CANCER: THE EARLY DETECTION TOOLS

The goal of early detection is to find the disease in its early stages when treatment is most likely to be effective. There are two widely used tests to aid in the early detection of prostate cancer. They are:

- **PSA** - This simple blood test measures the level of a protein called prostate-specific antigen (PSA). Normally, PSA is found in the blood at very low levels. Elevated PSA readings can be a sign of prostate cancer.
- **DRE** - The digital rectal exam (DRE) involves the physician inserting a lubricated, gloved finger into the rectum to feel the prostate for signs of cancer. This test is simple, safe and only slightly uncomfortable.

The most sensitive method for early detection uses **both** the PSA and DRE tests. Although PSA will detect most high-risk cancers, there are cancers that will be missed by this test and are detected by the DRE. Therefore, using both tests together will give your doctor the most accurate information.



## WHO IS AT RISK FOR PROSTATE CANCER?

All men, of appropriate age, should be counseled with regard to early detection for prostate cancer. The American Urological Association (AUA) encourages physicians to routinely offer prostate cancer testing to men who have an anticipated lifespan of 10 or more years and are:

- over the age of 50 years,
- over the age of 40 years and have a family history of the disease (for example, a father or brother who was diagnosed with prostate cancer), or
- over the age of 40 years and African-American

In addition, there are a number of warning signs that may indicate the presence of prostate cancer. While often due to other

non-cancerous causes, you should consult your physician if you are experiencing any of the following symptoms:

- difficulty with urination,
- frequent trips to the bathroom at night,
- pelvic discomfort,
- weight loss or
- persistent back pain.



## SHOULD YOU BE TESTED FOR PROSTATE CANCER?

Testing for prostate cancer is a personal decision that should be made by each patient with his physician. Patients should be aware of the advantages and disadvantages of early detection and treatment. Some additional information that you should be aware of includes:

- Men with a life expectancy of less than 10 years are unlikely to benefit from early detection and treatment of prostate cancer.
- Treatment of prostate cancer carries a risk of impotence (inability to have an erection) and incontinence (inability to control urine flow from the bladder).
- Studies to evaluate the benefits of early detection are in progress but not complete. Until these studies are completed, the value of early diagnosis is not certain.

You and your doctor should decide together whether you are a good candidate for prostate cancer testing. The AUA believes that monitoring PSA levels as part of your regularly scheduled check-ups offers doctors and patients the chance to establish baseline information, detect problems, and begin treatment before a cancer spreads and comes incurable.



## HOW WILL MY DOCTOR MAKE A DIAGNOSIS OF PROSTATE CANCER?

If your physician finds any warning signs with the PSA or DRE tests and you want further evaluation, you should be referred to a urologist. Urologists are doctors who specialize in treating prostate cancer and other conditions that affect the urinary tract and male reproductive organs.

Your chances of having prostate cancer depend on your age and your PSA level. As a rule, PSA levels below 4.0 ng/ml are considered normal. However, about 20% of prostate cancers are found in men whose PSA level is less than 4.0 ng/ml. Further evaluation should be considered for any level over 4.0 ng/ml or if the DRE is abnormal.

If the PSA or DRE tests suggest the presence of cancer, your urologist will discuss the option of a biopsy. A biopsy is the surgical removal of a small sample of tissue. Biopsies are usually performed in the doctor's office.



## WHEN IS A PROSTATE BIOPSY NEEDED?

Although an abnormal DRE or an elevated PSA may suggest the presence of prostate cancer, a diagnosis of cancer can only be confirmed by a prostate biopsy. A urologist should be consulted for a biopsy when any of the following findings is present:

- The PSA is 4.0 ng/ml or more.
- The PSA level increases significantly from one test to the next.
- The DRE is abnormal.

**Biopsies are minimally invasive procedures.** A small amount of prostate tissue is removed by a needle inserted through the rectum. An ultrasound probe is used to guide the needle. Usually this procedure is performed as an outpatient procedure without anesthesia.

After the prostate tissue is removed, it is examined under the microscope by a pathologist. If a tumor is present, the biopsy report will give the tumor a "grade." The tumor grade indicates how quickly the tumor is likely to grow and spread. Once a cancer is diagnosed, you and your physician can discuss treatment options and choose the type of treatment that is best suited to your needs.

### What Can I Expect After the Biopsy?

After the biopsy you may have side effects such as infection and minor rectal bleeding. Serious complications are unusual. Blood in the stool or urine usually disappears after a few days; blood in the semen usually disappears within a few weeks. Many physicians have their patients take antibiotics for a few days around the time of the biopsy.

If you are taking aspirin, arthritis medicine, or any medicine that thins the blood, you should tell your doctor. Your doctor may decide to discontinue these types of medicine prior to the biopsy. Also, if you have a heart murmur or any artificial or transplanted material in your body (such as a heart valve, hip, graft or other replacement material), you should tell your doctor. Special antibiotics may be used before, during and after the biopsy.



## FACING CANCER: WHAT TO DO IF CANCER IS DIAGNOSED

If you have been diagnosed with prostate cancer, there are a number of routine, pre-treatment tests available to tell if your disease has spread. This information is known as "staging." A thorough physical examination that includes measuring your PSA level can help identify whether you will benefit from these staging tests.

- **Computed Tomography (CT).** A CT scan is not necessary for most patients with newly diagnosed prostate cancer. This test is more useful for patients with a PSA of greater than 25.0 ng/ml.
- **Magnetic Resonance Imaging (MRI).** This test is also not commonly used for patients with newly diagnosed prostate cancer. It is more often used to assess a prostate tumor when the PSA is more than 25.0 ng/ml.
- **Bone Scan.** If your urologist suspects that the cancer has spread, a bone scan may be recommended. This test is generally not necessary

12 of 63  
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with localized prostate cancers when the PSA level is less than 20.0 ng/ml.

Because your choices about treatments often depend on these findings, it is important for you to know as much as you can about your disease.



## TREATMENT METHODS FOR PROSTATE CANCER

There are a number of treatment options for managing prostate cancer including “watchful waiting,” surgery, radiation therapy or hormone therapy. In some cases, it is useful to combine more than one type of treatment. Work with your doctor to decide which approach is best for you.

- **Surveillance.** (also known as “watchful waiting”) In some men with slow-growing prostate tumors that are found at an early stage, it may not be necessary to start an active treatment. Your physician will follow your progress closely and give you regular exams to check for cancer growth. The exams will indicate if and when active treatment should begin.

*advantage:* This approach has little impact on lifestyle and no side effects.

*disadvantage:* Possibility of the cancer advancing (and becoming incurable).

- **Surgery.** The surgical procedure that removes the entire prostate and the surrounding tissue is called a **radical prostatectomy**. It is done while the patient is under anesthesia. This treatment is recommended if the tumor is localized to the prostate and is used to treat the early stages of prostate cancer. If the cancer is truly localized to the prostate and the prostate is removed, the chance of death from prostate cancer is low. However, if the cancer has spread beyond the prostate, further treatments may be necessary.

*advantage:* The entire prostate (including all the cancer cells in the gland) is removed.

*disadvantage:* The disadvantage of this procedure is the risk of complications (such as impotence or incontinence) resulting from the surgery. Also, there is no guarantee that all the disease is removed.

- **Radiation Therapy.** This is another type of local therapy used to attack cancer cells only in the treated area. For prostate cancer in its early stages, radiation therapy can either be used instead of surgery or it can be used following surgery to destroy cancer cells that may remain. There are two forms of radiation treatment:

**1. External Beam Radiotherapy** treats the prostate with a carefully targeted beam of radiation from a machine. It is well-tolerated by most patients. Side effects vary and include inflammation of the rectum or bladder and impotence. In most cases, side effects are mild and short-lived. Hospitalization is not required. Patients receive treatment once a day, 5 days a week for a 6 to 8 week period.

**2. Brachytherapy** involves the placement of tiny radioactive “seeds” into the prostate. This option requires anesthesia but is generally performed without an overnight stay in the hospital.

*advantage:* Hospitalization is usually not required. Serious side effects are unusual.

*disadvantage:* Because the prostate remains in place, there is the possibility that some cancer cells remain in the body. Some patients may develop impotence.

- **Hormone Therapy.** Prostate cancer depends on male hormones, such as testosterone. Starving the cancer of hormones may slow or stop its growth. Hormone therapy is primarily used to halt or slow the spread of cancer. It does not cure the cancer.

There are two forms of hormone therapy. One approach involves surgically removing the testicles. The other form of hormone therapy involves injections of a drug, luteinizing hormone releasing hormone (LHRH) analog, every 30 to 120 days.

*advantage:* This approach is used to control prostate cancer that is anywhere in the body.

*disadvantage:* Side effects can include hot flashes, impotence, loss of sexual desire, breast swelling and tenderness and brittle bones.

- **Cryosurgery.** This option involves freezing the prostate tissue. The long-term effectiveness of this procedure is unknown.





## FOLLOW-UP CARE

Once you have been treated for prostate cancer, it is important to have regular follow-up exams to check for disease recurrence. Your doctor should suggest an appropriate follow-up schedule. This usually involves a check-up every 6 months for a PSA test and DRE.

The following changes in PSA levels may indicate the need for further treatment:

- PSA levels should decrease and remain at undetectable levels after radical prostatectomy. A detectable and rising PSA level following this procedure usually means the disease has returned.
- PSA levels should fall to a stable and low level after radiation therapy or cryosurgery. A rising PSA level is often associated with disease recurrence.
- The pattern of PSA rise after local therapy for prostate cancer can help distinguish between local and distant recurrence.

Fighting cancer is a challenging ordeal, and it is important that you feel you have support, information and counsel. Do not make a sudden decision. Talk to your physician and make sure that you ask all your questions and understand the answers. It is sometimes helpful to get a second opinion from another doctor. Family and support groups can also provide important information. Seek out other sources of information to help you stay on top of the issue. Gather and study information to make the best treatment choice for you.



## INFORM YOUR DOCTOR

Certain activities, conditions, and substances can also affect PSA levels, including:

- medicines (such as finasteride for male pattern baldness or BPH and other hormones),
- herbal medicines (such as PC-SPES),
- ejaculation within 48 hours of the test,
- testicular surgery – bilateral simple orchiectomy,
- prostate biopsy,
- urinary infection and
- indwelling catheter.

This Doctor's Guide for Patients is intended for patients and lay readers. It is intended to stimulate and facilitate discussion between the patient and doctor regarding the types of treatment described in summary fashion in this brochure. The American Urological Association, Inc. and its Best Practice Policy Committee developed the Prostate Specific Antigen Best Practice Policy, which is considered the basis for this publication. Best Practice Policies are consensus-based documents developed by a multi-disciplinary panel. The full report of the panel provides the physician with a more detailed discussion of treatment options to be considered.

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For additional copies of this brochure, physicians may contact:  
American Urological Association, Inc.®  
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Baltimore, MD 21201  
Phone: 410-223-4367

14 of 63  
3/1/2006



## RESOURCES FOR PATIENTS

The list below offers a good start to finding out more information on prostate cancer. These organizations are some of the most comprehensive cancer patient information and support organizations. Through their educational materials and on their web sites, you may also find other important resources.

### **American Cancer Society**

1599 Clifton Road, N.E.  
Atlanta, GA 30329-4251  
1-800-ACS-2345  
[www.cancer.org](http://www.cancer.org)

### **Cancer Information Service**

National Cancer Institute  
31 Center Drive MSC 2580 Building 31, Room 10A16  
Bethesda, MD 20892-2580  
1-800-4-CANCER  
[www.nci.nih.gov](http://www.nci.nih.gov)

### **US TOO!**

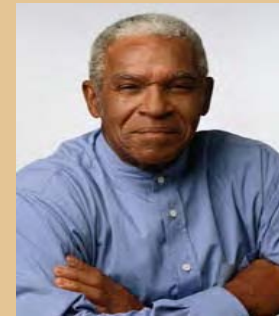
930 North York Road, #50  
Hinsdale, IL 60521-2993  
1-800-808-7866  
[www.ustoo.com](http://www.ustoo.com)

### **American Foundation for Urologic Disease (AFUD)**

1128 North Charles St, #401  
Baltimore, MD 21201-5559  
1-800-242-2383  
[www.afud.org](http://www.afud.org)

## **Appendix 2: Draft of culturally targeted prostate cancer brochure**





## Protect Your Prostate!

### What Black Men Need to Know for Good Choices and Good Health

*Includes a bonus section on free and  
low-cost prostate health screenings  
in the New York City area  
starting on page 11!*

This brochure was developed by  
the Barbara and Maurice A. Deane  
Prostate Health & Research Center  
and the Department of Oncological Sciences,  
Division of Cancer Prevention and Control  
Mount Sinai School of Medicine.





15. Bedford Stuyvesant Family Health Center  
1413 Fulton Street (718-636-4500)  
Free prostate cancer screening offered every other Saturday from 8:30-12:30 PM.
16. Woodhull Medical and Mental Health Center  
760 Broadway (718-963-8000)  
Prostate cancer screening is available with a doctor's referral.  
Free screening is offered in September.

## QUEENS

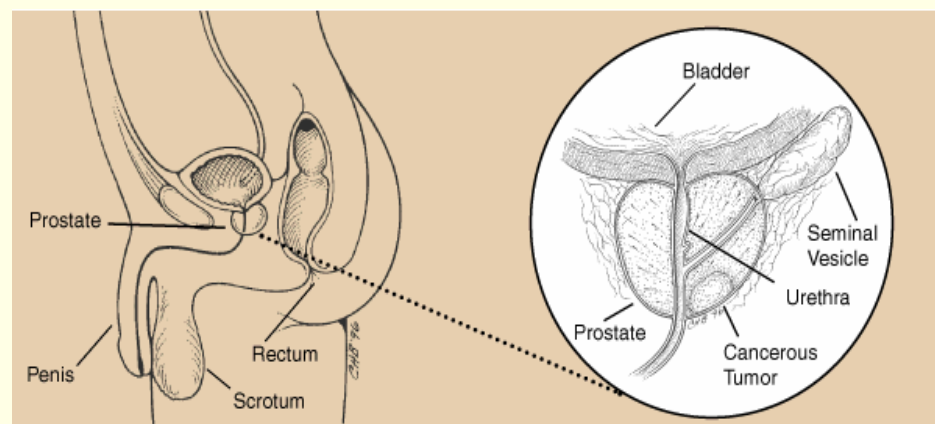
17. Addabbo Community Health  
67-10 Rockaway Beach Boulevard, Arverne (718-945-7150)  
Prostate cancer screening available for a sliding scale fee and actual screening is performed at other locations in the area.
18. Long Island Jewish Medical Center  
270-05 76<sup>th</sup> Avenue, New Hyde Park (516-465-2500)  
Free prostate cancer screening offered during monthly health fairs.
19. North Shore University Hospital at Forest Hills  
102-01 66<sup>th</sup> Road, Forest Hills (718-507-4400)  
Prostate cancer screening available with doctor's referral.
20. Park Health Center  
131-24 Rockaway Boulevard, South Ozone Park (718-659-7166)  
Free DRE exam is available. PSA test is \$50. Most insurances accepted. Prostate cancer screening is offered on Monday and Thursday.
21. Elmhurst Hospital Center  
79-01 Broadway, Elmhurst (718-334-4000)  
Free prostate cancer screening offered during September.
22. Queens Hospital Center Urology Clinic  
82-68 164<sup>th</sup> St., Jamaica (718-883-3142)  
Prostate cancer screening offered every Tuesday for a sliding scale fee.

## What is the prostate?

The prostate gland is part of the male reproductive system. It is about the same size and shape as a walnut. As shown in the picture below, the prostate surrounds the urethra, the tube that carries urine from the bladder through the penis. It is located below the bladder and in front of the rectum (the passageway through which stool or waste passes). The prostate produces fluid for semen.

## What are some problems a man can have with his prostate?

When a man is about 45 years of age, the prostate starts to naturally grow. This growth is made up of benign (not cancerous) tissue and is called benign prostatic hyperplasia, or BPH. BPH is not cancer and does not lead to cancer, but it can block the normal flow of urine. When the prostate increases, it squeezes the urethra and makes it difficult to urinate.

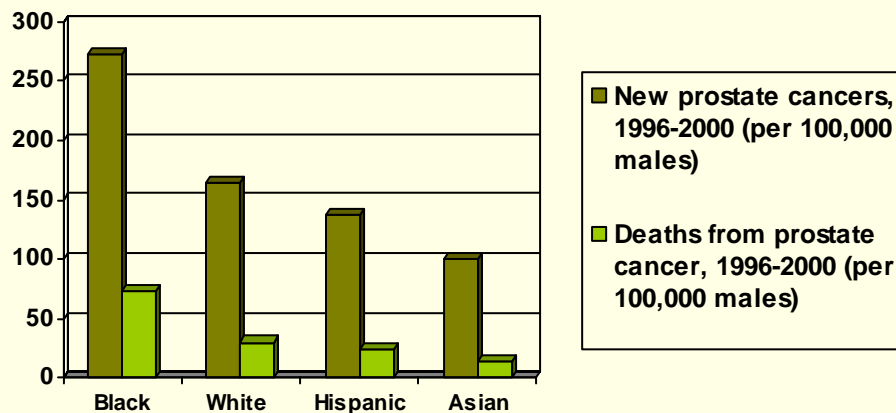


## What is prostate cancer?

Prostate cancer is a disease that affects the cells of the prostate. Normally, cells grow and divide in an orderly manner but sometimes cells can grow out of control. When this happens, tumors can form. Cancerous prostate tumors can block the flow of urine and, if untreated, can spread to other parts of the body.

## What are the facts about Black men and prostate cancer?

Prostate cancer is the second leading cause of male cancer deaths in the United States and accounts for more than 30,000 American deaths every year. Among Black men, rates of prostate cancer are higher than any other racial/ethnic group. As a group, Black men are 60% more likely than White men to get prostate cancer and are more likely to get it at younger ages. Black men are also twice as likely to die from this disease.



Data source: National Cancer Institute, 2003.

## Why are Black men more likely to get prostate cancer and die from it?

It is unclear why Black men are more likely to get prostate cancer compared to other racial and ethnic groups. Higher rates of prostate cancer among Black men may be due to genetics, as well as lifestyle factors, such as diets high in animal fat or red meat. Black men are also more likely to die of prostate cancer. This may be due to the fact that Black men are more likely to be diagnosed with the disease at a late and less curable stage.

8. Harlem Week Street Fair  
212-862-8477 or [www.harlemdiscover.com](http://www.harlemdiscover.com).  
Prostate cancer screening offered during street fair in late August.  
Go to website or call for details.
9. Ralph Lauren Center for Cancer Care and Prevention  
1919 Madison Ave. (212-987-1777)  
Free prostate cancer screening available.

### BRONX

10. East Tremont Medical Center  
930 East Tremont Avenue (718-620-6068)  
Prostate cancer screening available with doctor referral only and patient must have insurance. If patient has no insurance, screening costs \$75.
11. Lincoln Medical and Mental Health Center  
234 East 149<sup>th</sup> Street--9<sup>th</sup> floor (718-579-5550 or 718-579-5000)  
Free prostate cancer screening offered every Tuesday from 1-3 PM.
12. Montefiore Medical Center  
111 East 210<sup>th</sup> Street (718-920-5402)  
Free prostate cancer screening available.

### BROOKLYN

13. SUNY Downstate Medical Center  
University Hospital of Brooklyn  
450 Clarkson Avenue (718-270-3739 or 718-270-7673)  
Free prostate cancer screening available. Call for details.
14. New York Methodist Hospital  
506 6<sup>th</sup> Street (718-780-5367)  
Prostate cancer screening available with a doctor's referral and with either insurance or Medicaid. Free screening offered during September.

## Local Resources for Prostate Cancer Screening

Last updated July 2005

**\*Always call for more information\***

### MANHATTAN

1. Mount Sinai School of Medicine & Settlement Health  
212 East 106<sup>th</sup> Street (212-241-0045)  
Prostate cancer education and screening offered every second Thursday of each month at 5:30 PM.
2. Harlem Hospital Center  
530 Lenox Avenue (212-939-8051)  
Free prostate screening offered every Thursday at noon and Saturday at 9 AM.
4. Saint Vincent's Comprehensive Cancer Center  
325 West 15<sup>th</sup> Street (212-604-6000 )  
Prostate cancer education and screening offered during the month of June at this location and other locations throughout the city. For those locations call 1-800-CARE-421.
5. New York Presbyterian Hospital-Columbia Presbyterian  
Milstein Hospital Building  
177 Fort Washington Avenue (212-305-2543)  
Free prostate cancer screening available.
6. New York University Medical Center  
550 First Avenue (212-263-2266)  
Free prostate cancer screening available.
7. New York University Clinic at Bellevue Hospital  
462 First Ave. and 27th St. (212-562-3000)  
Prostate cancer screening available, free or for a sliding scale fee.

## What are the screening tests for prostate cancer?

There are two tests that are widely used for the early detection of prostate cancer.

- ♦ **Prostate Specific Antigen test (also called PSA test)** - This simple blood test measures the level of a protein called prostate-specific antigen (PSA). Normally, PSA is found in the blood at very low levels. In general, a normal PSA level is between 0 and 4. High levels of PSA in the blood can be a sign of prostate cancer. It is recommended that a man have a PSA test every year.
- ♦ **Digital Rectal Exam (also called DRE)** - The digital rectal exam (DRE) involves the doctor inserting a lubricated, gloved finger into the rectum to feel the prostate for signs of cancer. It is recommended that a man have a DRE every year.

## Who should be screened for prostate cancer?

You should talk to your doctor about prostate cancer screening if you are **a Black man and age 45 or older**. Prostate cancer screening is even more important to consider if you have a **family history** of the disease, especially first-degree relatives diagnosed with prostate cancer, such as a father or brother. If you have several first-degree relatives who had prostate cancer at an early age, you could begin testing at age 40.

You should also talk with your doctor if you experience any of the following warning symptoms:

- ♦ Difficulty with urination
- ♦ Frequent trips to the bathroom at night
- ♦ Discomfort
- ♦ Weight loss
- ♦ Persistent back pain.

These problems are not always caused by prostate cancer, but it is a good idea to let your doctor know about them.

## Are you concerned about the digital rectal exam?

Many men have concerns about the digital rectal exam (DRE). Does this sound like you?

“It’s not a normal thing for a man to do.”

“It will hurt.”

“It will be embarrassing.”

The truth is :

- ◆ DRE is a quick and common exam that your doctor probably gives to many of his or her patients.
- ◆ Most doctors care about giving the DRE in the most respectful way possible.
- ◆ It is usually painless and only a little uncomfortable. Many men who have had a DRE describe it as easy: “in and out.”
- ◆ The most sensitive way to detect prostate cancer at an early stage uses both the PSA and DRE tests. Although PSA will detect most high-risk cancers, it may miss some cancer that can be found by the DRE.

### **Check Yourself: “Do I need to be screened for prostate cancer if I don’t feel sick?”**

- ◆ Some men believe that if they don’t feel sick, prostate cancer isn’t something they have to think about now.
- ◆ The fact is that often men with early stage prostate cancer have NO symptoms.



## National Resources

### **American Cancer Society**

1599 Clifton Road, N.E.

Atlanta, GA 30329-4251

1-800-ACS-2345

[www.cancer.org](http://www.cancer.org)

Offices in all boroughs of NYC. Call for more details.

### **American Foundation for Urologic Disease, Inc.**

1000 Corporate Boulevard, Suite 410

Linthicum, MD 21090

1-800-828-7866

[www.afud.org](http://www.afud.org)

### **Cancer Information Service**

National Cancer Institute

9000 Rockville Pike

Bethesda, MD 20892

1-800-4-CANCER

[www.cancer.gov](http://www.cancer.gov)

### **Centers for Disease Control and Prevention**

1600 Clifton Road

Atlanta, GA 30333

1-800-311-3435

[www.cdc.gov](http://www.cdc.gov)

### **National Prostate Cancer Coalition**

1154 Fifteenth Street, NW

Washington, DC 20005

1-800-245-9455

[www.pcacoalition.org](http://www.pcacoalition.org)

### **US TOO!**

5003 Fairview Avenue

Downers Grove, IL 60515

PCa Support Hotline: 1-800-808-7866

[www.ustoo.com](http://www.ustoo.com)



### **Check Yourself: “I’m worried about side effects.”**

- ◆ In general, prostate cancer screening is **not** linked to any negative side effects or problems.
- ◆ Some men believe that, if they are diagnosed with prostate cancer, the treatment would cause their sex life to suffer or make them unable to hold their urine.
- ◆ The fact is that different treatments have different side effects. Since no one treatment has proven to be the best, a man diagnosed with prostate cancer can choose the treatment best for him with his doctor’s help.

### **What can a man do to prevent prostate cancer?**

So far, little is known about what causes prostate cancer, so it is difficult to say how to prevent it. There are some risk factors that increase the chances that a man will get prostate cancer. A man has little control over some of these factors, such as:

- ◆ Being African American or Black and age 45 or older
- ◆ Having family history of prostate cancer, especially a first-degree relatives (such as a father or brother) who had the disease

One risk factor that a man does have some control over is **diet**.

- ◆ Prostate cancer has been found to be related to a diet high in animal fat and red meat.

There have been studies that suggest that certain diets may **protect** a man against prostate cancer but there is still much that is unknown and research is still being done. Such diets may be those high in:

- ◆ Fruits and vegetables
- ◆ Selenium, an element found in grains, fish and meat
- ◆ Lycopene, a compound in cooked tomato products and watermelon.

### **Check Yourself: “I don’t have time to get screened for prostate cancer.”**



- ◆ Some men feel too busy with work and family to make an appointment to be screened for prostate cancer.
- ◆ It’s easy to put off getting screened. Sometimes it’s hard to get to a doctor or schedule an appointment.
- ◆ Screening can help you to stay healthy so you can continue to be there for your family.

### **Is there controversy over prostate cancer screening?**

There is controversy over prostate cancer screening because doctors and medical organizations disagree about whether men should be screened on a regular basis. Prostate cancers found through the PSA test are more likely to be early-stage cancers that have not spread outside the prostate. When the cancer spreads outside the prostate, it becomes more difficult to manage and the risk of death rises. However, research studies looking at large numbers of men report different findings with regard to early detection and death from prostate cancer. Some studies have found that early detection of prostate cancer results in fewer deaths overall while other studies have not found that early detection lowers prostate cancer deaths. You should talk to your doctor about this controversy before you are screened for prostate cancer.

### **Do you have a doctor you trust?**

A number of Black men say they have problems with their doctors and other health care providers. Some men feel that doctors don’t take enough time to explain different medical tests and procedures. Others feel that doctors don’t treat them with respect or they don’t trust doctors and hospitals. If you are still looking for a doctor who you feel comfortable with, check the resources at the back of this booklet starting on page 10. These resources may help you find a doctor or a place for prostate care and screening that you trust.

## What can I expect after I get screened?

If your doctor finds any warning signs with the PSA or DRE tests, you should be referred to a urologist for further evaluation. Urologists are doctors who specialize in treating prostate cancer and other conditions that affect the urinary tract and male reproductive organs.



## When is a prostate biopsy needed?

Although an abnormal DRE or PSA test may suggest the presence of prostate cancer, prostate cancer can only be diagnosed through a prostate biopsy. A biopsy is the removal of a small amount of prostate tissue through surgery. After the prostate tissue is removed, it is examined under a microscope. If there is a cancerous tumor, the biopsy report will give the tumor a “grade.” The tumor grade will show how quickly the tumor may grow and spread. Depending on what diagnosis you receive, you and your doctor can discuss treatment options and choose the type of treatment that is best for you.

### **Check Yourself: “I don’t want to know if I have prostate cancer.”**

- ♦ Some men are afraid to be screened for prostate cancer because they are afraid of learning they have the disease.
- ♦ Knowing that you have prostate cancer can be worrying.
- ♦ However, the sooner you know, the more control you have over the situation by making choices about what to do next.



## What are the treatments for prostate cancer?

There are many treatment options for managing prostate cancer. In some cases, it is useful to combine more than one type of treatment.

- 1. Watchful waiting (also known as surveillance):** If you have a slow-growing tumor that is found at an early stage, you may not need to start an active treatment. Your doctor will give you regular exams to check for cancer growth. The exams will indicate if and when active treatment should begin.
- 2. Surgery:** The surgical removal of the entire prostate is recommended if you have a tumor that is localized to the prostate, and the cancer is in the early stages. If the cancer has spread beyond the prostate, further treatments may be necessary.
- 3. Radiation therapy:** Radiation is used to kill cancer cells in the prostate. The radiation is passed through the prostate by a machine, or placed inside the prostate in “seeds” (also called brachytherapy). For prostate cancer in its early stages, radiation therapy can either be used instead of surgery, or it can be used after surgery to destroy cancer cells that may be left behind.
- 4. Hormone therapy:** Prostate cancer depends on male hormones, like testosterone, to grow. Hormone therapy involves reducing the amount of male hormones in the body to stop or slow the spread of cancer. Hormone therapy does not cure the cancer.

If you are diagnosed with prostate cancer, you and your doctor should decide together what treatment is best for you.



## Appendix 3: Randomized control trial baseline questionnaire

1. Sociodemographic, Health Status, and Healthcare Access Information: We will assess sociodemographic and variables (e.g., age, marital status, parental status, education, income), healthcare access variables (e.g., health insurance status, sources of health care, satisfaction with healthcare) and perceived health status as well as family history of cancer.
2. Physician recommendation of Prostate Cancer (PCa) Screening: We will ask participants if a physician has ever explained the advantages or disadvantages of PSA test and DRE test, as well as ask if a physician has ever recommended either test.
3. Past PSA test /DRE Participation, Attitudes, Intention & Behavioral Control: Based on the Theory of Planned Behavior, we will assess the following:
 

*Participation*: We will ask participants if they have ever had a PSA test or DRE, the date of their last tests, their age at their first test, and how many they have had in their lifetime.

*Attitudes*: Eight items related to attitudes towards PSA test and DRE will be included, based on the work of Sheeran and Orbell (1).

*Behavioral Control*: Two will be used to assess participants' sense of how easy it will be to participate in DRE and PSA and how much control they have over doing so. These items were adapted from Sheeran and Orbell (1).

*Intention*: One item will be used to assess intention to be screened for prostate cancer based on the work of Sheeran and Orbell (1).
4. Perceived Prostate Cancer Risk: Perceived risk will be assessed through rating scales ranging from 0 to 100 that ask participants to indicate how likely it is that they will develop PCa and how serious they think it would be if they developed PCa. This scale is adapted from Weinstein (2) who observed likelihood by severity interactions for health-protective behaviors. Three additional items that do not rely on numerical estimates were developed by the PI in order to assess perception of personal risk. Finally, similar questions were asked about perceived risk of heart disease in order to determine whether perceived PCa risk was based on realistic estimates or reflect unusually negative personal risk evaluations.
5. PCa and Screening Knowledge: Ten items will be used to assess participant's knowledge of PCa risk factors, symptoms, and disease course. Participants awareness of the PCa screening controversy is also assessed, as well as perceptions of population PCa risk. The majority of these items have been used in previous studies (3-7).
6. PCa Screening Behavioral and Control Beliefs: Forty-four items will assess favorable and unfavorable attitudes (perceived advantages and disadvantages) of PCa screening. These items have been included in several studies of PCa screening and other types of cancer screening, and internal reliability ranges from moderate to high (.77 - .90) (8) (3;6;9).
7. PCa Screening Social Influence/Normative Beliefs: Three items will be used to assess the social influence of significant others in participants' PCa screening decisions. Ten additional items were developed by the PI and colleagues, will be used to participants' perceptions of social influence from other African American (AA) men to participate in regular PCa screening, as well as perception of reference group norms regarding surveillance. This measure also includes items that assess the social influence of significant others, such as family, friends, etc. The response key is a Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). In previous work by the PI, these items had strong reliability ( $\alpha = .80$ ).
8. Medical Mistrust: The Group-Based Medical Mistrust Scale (GBMMS) will be used to assess suspicion of mainstream health care systems and health care professionals and the treatment provided to individuals of the respondent's ethnic or racial group. The GBMMS is a 12-item scale created by the PI and colleagues that has demonstrated strong reliability in AA and Latino samples ( $\alpha = .83$ ) (10).
9. Ethnic Identity: The Centrality subscale of the Multidimensional Inventory of Black Identity (11) will be used to assess ethnic/racial identity. The subscale includes 8 items and has strong reliability ( $\alpha = .77$ ).
10. Profile of Mood States (POMS): In order to control for the effect of mood and psychological state on healthcare participation, including PCa screening, we have included POMS (12) which assesses mood on several dimensions during the past week using self-descriptive adjectives rated on a five-point scale. This 22-item version of the POMS, developed by Carver et al. (12), has been widely used in studies of interventions with cancer patients.
11. Avoidance of Healthcare: The Avoids Contact with Health Care scale has been added to the assessment battery. This 4-item scale was developed by Rakowski et al. (13) will be used to assess the tendency to avoid healthcare providers and to use home remedies. This scale demonstrated adequate reliability ( $\alpha = .66$ ) in published work (13).

12. Perceived Access to Healthcare Services: Perceived access to PCa screening will be assessed by 10 items that address cost, convenience and the existence of a health care provider relationship. It is adapted from the Perceived Access to Health Services (PAHS) scale (14).
13. Collectivism will be assessed using a 6-item measure of one's belief that the basic unit of society is the family rather than the individual. These items have demonstrated strong reliability in AA female samples ( $\alpha = .93$ ) (15).

#### References

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## Section Measures

1. Background Information
2. Healthcare Information
3. Current Health Status, Personal History of Cancer, Family History of Cancer
4. Past DRE Participation, Attitudes, Norms, Intention & Behavioral Control
5. Past PSA Test Participation, Attitudes, Norms, Intention & Behavioral Control
6. Perceived Prostate Cancer Risk
7. Prostate Cancer Screening Knowledge
8. Prostate Cancer Screening Behavioral and Control Beliefs
9. Prostate Cancer Screening Social Influence/Normative Beliefs
10. Medical Mistrust
11. Ethnic Identity
12. Profile of Mood States
13. Avoidance of Healthcare
14. Behavioral Control/ Perceived Access to Healthcare Services
15. Collectivism

## Section 1

1. What is your date of birth? \_\_\_\_\_ How old are you? \_\_\_\_\_
2. What type of relationship are you in?
  - ☐ Married or living with partner
  - Divorced
  - Widowed
  - Separated
  - Never Married
3. Do you have any children? ☐ Yes ☐ No
4. Your place of birth (city, state, country) \_\_\_\_\_
5. Do you consider yourself to be of Latino or Hispanic origin? Yes No
6. If you said yes, do you consider yourself to be any of the following? **(Check all that apply)**
  - Mexican/Mexican-American/Chicano
  - Puerto Rican
  - Cuban
  - Central American (What Country? \_\_\_\_\_)
  - Dominican
  - Other \_\_\_\_\_
7. How would you describe yourself? Answer even if you are Latino or Hispanic. **(Check all that apply)**
  - Black/African-American
  - Black/African (Ethnic Group, for example Yoruba, Wolof, etc.? \_\_\_\_\_)
  - Black/Caribbean (Ethnic Group, for example Jamaican, Guyanese, etc.? \_\_\_\_\_)
  - Black/Latino
  - Asian (Ethnic Group, for example, Chinese, Korean, etc.? \_\_\_\_\_)
  - Native American/American Indian (Ethnic Group \_\_\_\_\_)
  - White
  - Other race (\_\_\_\_\_)
8. What is your current job status?
  - Currently employed (full time or part time)
  - Unemployed
  - Retired
  - Other (for example, student, on disability)
9. What is the highest level of education you have completed?
  - ☐ Graduate or professional degree (Ph.D., M.D., J.D., MBA, etc.)
  - ☐ College or university graduate (4-year degree)
  - Associate's Degree (2-year degree)
  - ☐ Some college training (including technical school, junior college, nursing school, etc.)
  - ☐ High School graduate or GED
  - ☐ Less than high school
10. What is your approximate annual total household income (before taxes):
  - ☐ Less than \$10,000
  - ☐ \$10,000 - \$19,999
  - ☐ \$20,000 - \$39,999
  - ☐ \$40,000 - \$59,999
  - ☐ \$60,000 - \$79,999
  - ☐ \$80,000 - \$99,000
  - ☐ \$100,000 or more

## Section 2

1a. A primary care doctor is a doctor who is trained to give you basic care. Your primary care doctor is the doctor you see first for most health problems. Do you have a regular primary care doctor who you usually go to when you are sick or need healthcare?

☐ Yes

☐ No

If YES, please answer questions 1b and 1c. If NO, skip to question 2.

1b. What is your primary care doctor's race or ethnic background? **(Check all that apply)**

White

Black/African-American

Latino/Hispanic

Native American/American Indian

Asian

Some other race (Which race? \_\_\_\_\_)

1c. What is your primary care doctor's gender?

☐ Female

☐ Male

2. Where do you usually go when you are sick or need healthcare?

Doctor's office or private clinic

Community health center or other public clinic

Hospital outpatient department

Hospital emergency room

Some other place (Where? \_\_\_\_\_)

3. What type of health insurance do you have?

Medicaid or Medicare

Employer-provided insurance (for example Oxford, Blue Cross/Blue Shield)

Pay for insurance out-of-pocket

I do not have health insurance

Other \_\_\_\_\_

Not sure

4. When was your last physical examination?

☐ Within the past year

☐ 1 - 2 years ago

☐ 2 - 3 years ago

☐ More than 3 years ago

☐ I'm not sure

5. During the last 12 months, was there any time when you had a medical problem but put off, postponed, or did not seek medical care?

☐ Yes

☐ No

☐ I'm not sure

6. During the last 12 months, was there any time you did not follow a doctor's advice, treatment plan, get a recommended test, or see a doctor you were referred to?

☐ Yes

☐ No

☐ I'm not sure

7. How much do you agree with the following statement: **"Overall, I am satisfied with the healthcare I receive."**

☐ Strongly disagree

☐ Disagree

☐ Agree

☐ Strongly agree

### Section 3

1. In general, compared to other Black men your age, would you say your health is:
- ☐ Excellent      ☐ Very good      ☐ Good      ☐ Fair      ☐ Poor
2. We are interested in understanding the health history of your family—in particular, their history of cancer. We are only interested in relatives who are related to you by blood, including half-siblings. This does not include adopted relatives, step-relatives, or in-laws.

**Instructions:** Please list any blood relatives (for example, mother, father, brothers, sisters, grandparents) who have been diagnosed with cancer. For each relative listed, you will also answer a few other questions. An example is provided below. Continue on the back of this page if necessary.

Relative	Type of cancer	How old was <u>your relative</u> when he/she was diagnosed with cancer?	Did your relative die of cancer?
(ex:) Mother	Breast	60	No

### Section 4

A **Digital Rectal Examination (DRE)** is a finger test of the prostate (doctor places a gloved finger in the rectum or rear end). We would like for you to think only of the DRE when answering the next set of questions.

- 1a. Has a doctor ever explained to you the **advantages** of a DRE?
- ☐ Yes      ☐ No      ☐ I'm not sure
- 1b. Has a doctor ever explained to you the **disadvantages** of a DRE?
- ☐ Yes      ☐ No      ☐ I'm not sure
2. Has a doctor ever recommended that you have a DRE to check for prostate cancer?
- ☐ Yes      ☐ No      ☐ I'm not sure
3. Was there ever a time when you **did not** have a DRE when it was offered because you refused it?
- ☐ Yes      ☐ No      ☐ It's never been offered to me
- If YES, why did you refuse?** \_\_\_\_\_
4. Have you ever had a DRE to check for prostate cancer?
- ☐ Yes      ☐ No      ☐ I'm not sure

**If NO or NOT SURE, skip to question 10. If YES, continue to question 5.**

5. How old were you when you had your first DRE to check for prostate cancer? \_\_\_\_\_
6. How many DRE's have you had in your lifetime to check for prostate cancer?
- ☐ None  
☐ 1 – 2  
☐ 3 – 5  
☐ 6 – 10  
☐ More than 10
7. When was the date of your last DRE? Date: \_\_\_\_\_
- ☐ Within the past 6 months  
☐ Between 7 and 12 months ago  
☐ Between 1 and 2 years ago  
☐ Between 2 and 3 years ago  
☐ 3 – 5 years ago  
☐ More than 5 years ago  
☐ I'm not sure

8. Where did you receive your last DRE?
- Doctor's office or private clinic
  - Community health center or other public clinic
  - Hospital outpatient department
  - Hospital emergency room
  - Community health fair
  - Screening sponsored by a community organization
  - Screening sponsored by a church
  - Some other place (Where? \_\_\_\_\_)
9. Were the results of your last DRE normal? ☐ Yes ☐ No ☐ I'm not sure
10. How much do you agree or disagree with this statement: **"I intend to have a DRE in the next 6-7 months?"**
- ☐ Strongly disagree
  - ☐ Disagree
  - ☐ Undecided/neither agree nor disagree
  - ☐ Agree
  - ☐ Strongly agree
11. When do you plan to have your next DRE?
- ☐ Within the next 1 – 7 months
  - ☐ 8 -12 months from now
  - ☐ 1 - 2 years from now
  - ☐ More than 2 years from now
  - ☐ When my doctor recommends one
  - ☐ When I have symptoms or problems
  - ☐ I have no plan to have one
  - ☐ Not sure
12. How much control do you have over getting a DRE?
- ☐ Complete control
  - ☐ A lot of control
  - ☐ A fair amount of control
  - ☐ Very little control
  - ☐ No control
13. Having a DRE would be....
- ☐ Very easy
  - ☐ Easy
  - ☐ Difficult
  - ☐ Very difficult

**Please read the following statements. Think about how much you agree or disagree with each statement and circle the number that best matches your opinion.**

**Do you think that getting a DRE would be...**

		Strongly Disagree	Disagree	Undecided/ Neither agree nor disagree	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5



16. Please complete the following statement: **“If I were going to get a DRE, I would prefer to have it done by a doctor or healthcare provider of...”**

- ☐ My own race or ethnic group
- ☐ Another race or ethnic group
- ☐ I have no preference

17. Please complete the following statement: **“If I were going to get a DRE, I would prefer to have it done by a doctor or healthcare provider who is...”**

- ☐ Male
- ☐ Female
- ☐ I have no preference

## Section 5

**A Prostate Specific Antigen (PSA) test is a special blood test that checks for prostate cancer. We would like for you to think only of the PSA test when answering the next set of questions.**

1a. Has a doctor ever explained to you the **advantages** of a PSA test?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

1b. Has a doctor ever explained to you the **disadvantages** of a PSA test?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

2. Has a doctor ever recommended that you have a PSA test to check for prostate cancer?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

3. Was there ever a time when you **did not** have a PSA test when it was offered because you refused it?

- ☐ Yes
- ☐ No
- ☐ It's never been offered to me

**If YES, why did you refuse?** \_\_\_\_\_

4. Have you ever had a PSA test to check for prostate cancer?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

**If NO or NOT SURE, skip to question 10. If YES, continue to question 5.**

5. How old were you when you had your first PSA test to check for prostate cancer? \_\_\_\_\_

6. How many PSA tests have you had in your lifetime to check for prostate cancer?

- ☐ None
- ☐ 1 – 2
- ☐ 3 - 5
- ☐ 6 – 10
- ☐ More than 10

7. When was the date of your last PSA test? Date: \_\_\_\_\_

- ☐ Within the past 6 months
- ☐ Between 7 and 12 months ago
- ☐ Between 1 and 2 years ago
- ☐ Between 2 and 3 years ago
- ☐ 3 – 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure

8. Where did you have your last PSA test?

- Doctor's office or private clinic
- Community health center or other public clinic
- Hospital outpatient department
- Hospital emergency room
- Community health fair
- Screening sponsored by a community organization
- Screening sponsored by a church
- Some other place (Where? \_\_\_\_\_)

9. Were the results of your last PSA test normal? ☐ Yes ☐ No ☐ I'm not sure

10. How much do you agree or disagree with this statement: **"I intend to have a PSA test in the next 6-7 months?"**

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided/neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

11. When do you plan to have your next PSA test?

- ☐ Within the next 1 – 7 months
- ☐ 8 -12 months from now
- ☐ 1 - 2 years from now
- ☐ More than 2 years from now
- ☐ When my doctor recommends one
- ☐ When I have symptoms or problems
- ☐ I have no plan to have one
- ☐ Not sure

12. How much control do you have over getting a PSA test?

- ☐ Complete control
- ☐ A lot of control
- ☐ A fair amount of control
- ☐ Very little control
- ☐ No control

13. Having a PSA test would be....

- ☐ Very easy
- ☐ Easy
- ☐ Difficult
- ☐ Very difficult

**Please read the following statements. Think about how much you agree or disagree with each statement and circle the number that best matches your opinion.**

**Do you think that getting a PSA test would be...**

		Strongly Disagree	Disagree	Undecided/ Neither agree nor disagree	Agree	Strongly Agree
a.	Worthwhile	1	2	3	4	5
b.	Worrying	1	2	3	4	5
c.	Reassuring	1	2	3	4	5
d.	Embarrassing	1	2	3	4	5
e.	Wise	1	2	3	4	5
f.	Healthy	1	2	3	4	5
g.	Unpleasant	1	2	3	4	5
h.	Important	1	2	3	4	5

18. Please complete the following statement: **“If I were going to get a PSA test, I would prefer to have it done by a doctor or healthcare provider of...”**

- ☐ My own race or ethnic group
- ☐ Another race or ethnic group
- ☐ I have no preference

19. Please complete the following statement: **“If I were going to get a PSA test, I would prefer to have it done by a doctor or healthcare provider who is...”**

- ☐ Male
- ☐ Female
- ☐ I have no preference

## Section 6

1. On a scale of 0% to 100% where 0 means “no chance” and 100 means “guaranteed to happen,” how would you rate your chances of getting prostate cancer? \_\_\_\_\_%
2. Please think about other black men your age with a similar family history of cancer. Compared to those men what do you think your chances are of getting prostate cancer?
  - ☐ I am at much less risk than others
  - ☐ I am at somewhat less risk than others
  - ☐ My risk is about the same as others
  - ☐ I am at somewhat higher risk than others
  - ☐ I am at much higher risk than others
3. On a scale of 0% to 100% where 0 means “not bad at all” and 100 means “the worst possible situation,” how bad would it be if you were to get prostate cancer? \_\_\_\_\_%
4. On a scale of 0% to 100%, what percentage of Black men do you think will get prostate cancer? \_\_\_\_\_%
5. How worried are you about getting prostate cancer?
  - ☐ Extremely worried
  - ☐ Moderately worried
  - ☐ A little worried
  - ☐ Not at all worried
6. Please think of other Black men your age with a similar family history of cancer. Compared to those men, what do you think your chances are of getting some other type of cancer, besides prostate cancer?
  - ☐ I am at much less risk than others
  - ☐ I am at somewhat less risk than others
  - ☐ My risk is about the same as others
  - ☐ I am at somewhat higher risk than others
  - ☐ I am at much higher risk than others
7. How worried are you about getting some other type of cancer, besides prostate cancer?
  - ☐ Extremely worried
  - ☐ Moderately worried
  - ☐ A little worried
  - ☐ Not at all worried
8. Compared to other Black men your age with a similar family history of heart disease (high blood pressure, stroke, heart attack, etc.), what do you think your chances are of being diagnosed with heart disease?
  - ☐ I am at much less risk than others
  - ☐ I am at somewhat less risk than others
  - ☐ My risk is about the same as others
  - ☐ I am at somewhat higher risk than others
  - ☐ I am at much higher risk than others
  - ☐ I have already been diagnosed with heart disease

9. How worried are you about developing heart disease?
- ☐ Extremely worried
  - ☐ Moderately worried
  - ☐ A little worried
  - ☐ Not at all worried
  - ☐ I have already been diagnosed with heart disease
10. How upsetting was it to think about and answer Question 1 about your chances of getting prostate cancer?
- ☐ Not at all
  - ☐ A little
  - ☐ Moderately
  - ☐ Quite a bit
  - ☐ Extremely
11. How upsetting was it to think about and answer Question 2 about your chances of getting prostate cancer compared to other Black men?
- ☐ Not at all
  - ☐ A little
  - ☐ Moderately
  - ☐ Quite a bit
  - ☐ Extremely
12. How upsetting was it to think about and answer Question 3 about how bad it would be if you were to get prostate cancer?
- ☐ Not at all
  - ☐ A little
  - ☐ Moderately
  - ☐ Quite a bit
  - ☐ Extremely

### Section 7

Please read the following statements. Think about how much each statement is true or false and select the box that best matches your answer.

1.	The prostate produces fluid for semen.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
2.	A man who has prostate cancer will always have symptoms.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
3.	Pain or discomfort in your back or pelvic area could be a sign of prostate cancer.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
4.	Finding prostate cancer at an early stage increases the chance of a cure.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
5.	A man is more likely to develop prostate cancer if his father or brother had it.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
6.	Black men are at higher risk for developing prostate cancer than White men.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
7.	If a man has a PSA test, he doesn't need to have a digital rectal exam.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
8.	Men with a life expectancy of 10 years or less (usually age 70 or older) may not benefit from prostate cancer screening.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
9.	If a man is diagnosed with prostate cancer, no treatment (also called watchful waiting) may be an option offered by his doctor.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
10.	All doctors and medical organizations agree that men age 40 and older should be checked for prostate cancer every year.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure

## Section 8

Please read the following statements. Think about how much you agree or disagree with each statement and circle the number that best matches your opinion.

The following questions ask about prostate cancer screening: Both the PSA test and DRE.

		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Undecided/Ne ither agree or disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
1.	Prostate cancer screening can find cancer early.	1	2	3	4	5
2.	Prostate cancer screening is something I try to put off.	1	2	3	4	5
3.	Prostate cancer screening can result in early treatment for cancer.	1	2	3	4	5
4.	Prostate cancer screening will let me know if I have cancer.	1	2	3	4	5
5.	Prostate cancer screening will let me know that I am well.	1	2	3	4	5
6.	If I feel healthy, I don't need to be screened for prostate cancer.	1	2	3	4	5
7.	Prostate cancer screening will help me to live longer.	1	2	3	4	5
8.	I don't know where to go for prostate cancer screening.	1	2	3	4	5
9.	People important to me would be reassured if I were screened for prostate cancer.	1	2	3	4	5
10.	Prostate cancer screening would give me peace of mind.	1	2	3	4	5
11.	If I learned I had prostate cancer, I would be afraid of impotence (not being able to perform sexually).	1	2	3	4	5
		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Undecided/Ne ither agree or disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
12.	If I learned I had prostate cancer, I would be afraid of incontinence (not being able to control urination or bowel movements).	1	2	3	4	5
13.	It is not important for me to go for prostate screening because I have no family history of prostate cancer.	1	2	3	4	5
14.	It is unlikely that I will get prostate cancer.	1	2	3	4	5
15.	If there is any chance that prostate cancer screening tests are not safe, I do not want to have them.	1	2	3	4	5
16.	The results of prostate cancer screening tests cannot be trusted.	1	2	3	4	5
17.	It is very likely that prostate cancer screening tests will miss something.	1	2	3	4	5

18.	Prostate cancer screening tests are risky.	1	2	3	4	5
19.	Prostate cancer screening is painful.	1	2	3	4	5
20.	I don't know what kind of doctor does prostate cancer screening.	1	2	3	4	5
21.	I would probably be treated rudely or disrespectfully if I go for prostate cancer screening.	1	2	3	4	5
22.	I am afraid to go for prostate cancer screening because I might find out something is wrong.	1	2	3	4	5
23.	Doctor's hours are not convenient for me to go for prostate cancer screening.	1	2	3	4	5
		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Undecided/Neither agree or disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
24.	I'm too busy to go for prostate cancer screening.	1	2	3	4	5
25.	I have to take time off from work to go for prostate cancer screening.	1	2	3	4	5
26.	Prostate cancer screening costs too much.	1	2	3	4	5
27.	I would probably have to wait too long in the doctor's office when I go for prostate cancer screening.	1	2	3	4	5
28.	It takes too long to make an appointment for prostate cancer screening.	1	2	3	4	5
29.	I don't have transportation to get to a place where I could be screened for prostate cancer.	1	2	3	4	5
30.	Prostate cancer screening is embarrassing.	1	2	3	4	5
31.	I would be ashamed if prostate cancer screening found that I have prostate cancer.	1	2	3	4	5
32.	Other people would view me negatively if a prostate cancer screening found that I had prostate cancer.	1	2	3	4	5
33.	I would be angry if prostate cancer screening found that I had prostate cancer.	1	2	3	4	5
34.	I would be frightened if a prostate cancer screening found that I had prostate cancer.	1	2	3	4	5
35.	I would not be able to handle it emotionally if prostate cancer screening found that I had prostate cancer.	1	2	3	4	5
36.	I would feel a sense of hopelessness and despair if prostate cancer screening found that I had prostate cancer.	1	2	3	4	5

**The following questions ask about Digital Rectal Exam (DRE).**

		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Undecided/Neither agree or disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
37.	DRE is embarrassing.	1	2	3	4	5
38.	DRE is an important part of prostate cancer screening.	1	2	3	4	5
39.	DRE is uncomfortable.	1	2	3	4	5
40.	DRE is painful.	1	2	3	4	5
41.	I would be ashamed to have a DRE.	1	2	3	4	5
42.	Having a DRE would make me feel like less of a man.	1	2	3	4	5
43.	DRE is quick.	1	2	3	4	5
44.	I don't feel comfortable talking to my doctor about DRE.	1	2	3	4	5

**Section 9**

1. Most people who are important to you think you should be screened for prostate cancer.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

2. People who are important to you have encouraged you to be screened for prostate cancer.

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Not Sure
- ☐ Agree
- ☐ Strongly Agree

3. If you have had a PSA test or DRE in the past, how was that decision influenced by the encouragement of people who are important to you?

- ☐ Not at all
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

Please answer each of the following statements based on your experiences in the past 12 months. Think about how much you agree or disagree with each statement and circle the number that best matches your opinion.

IN THE PAST 12 MONTHS...

		Strongly Disagree	Disagree	Undecided/ Neither agree nor disagree	Agree	Strongly Agree
1.	I have talked to or heard from men who have been screened for prostate cancer.	1	2	3	4	5
2.	I have talked to or heard from men who benefit from regular prostate cancer screening.	1	2	3	4	5
3.	I have received information about prostate cancer screening that is useful to me as a Black man.	1	2	3	4	5
4.	I have received trustworthy information about regular prostate cancer screening.	1	2	3	4	5
		Strongly Disagree	Disagree	Undecided/ Neither agree nor disagree	Agree	Strongly Agree
5.	I have talked to or heard from friends who think I should be screened for prostate cancer.	1	2	3	4	5
6.	I have talked to or heard from my spouse or partner who thinks I should be screened for prostate cancer.  <input type="checkbox"/> <i>I have no spouse or partner</i>	1	2	3	4	5
7.	I have talked to or heard from family members who think I should be screened for prostate cancer.	1	2	3	4	5
8.	I have talked or heard from people in my church or house of worship who think I should be screened for prostate cancer.  <input type="checkbox"/> <i>I have no church or house of worship</i>	1	2	3	4	5
9.	I have talked to or heard from doctors or other healthcare providers who think I should be screened for prostate cancer.	1	2	3	4	5
10.	I have talked to or heard from other Black men who think I should be screened for prostate cancer.	1	2	3	4	5



## Section 10

These questions ask about your beliefs about the care you and other people of your racial and ethnic group receive in from doctors, nurses and other staff people in the health care system. Please read the following statements. Think about how much you agree or disagree with each statement and circle the number that best matches your opinion.

		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Undecided</b>	<b>Agree</b>	<b>Strongly Agree</b>
1.	Doctors and health care workers sometimes hide information from Black people.	1	2	3	4	5
2.	Doctors have the best interests of people of Black people in mind.	1	2	3	4	5
3.	Black people should not confide in doctors and health care workers because it will be used against them.	1	2	3	4	5
4.	Black people should be suspicious of information from doctors and health care workers.	1	2	3	4	5
5.	Black people cannot trust doctors and health care workers.	1	2	3	4	5
6.	Black people should be suspicious of modern medicine.	1	2	3	4	5
7.	Doctors and health care workers treat Black people like "guinea pigs."	1	2	3	4	5
8.	Black people receive the same medical care from doctors and health care workers as people from other groups.	1	2	3	4	5
9.	Doctors and health care workers do not take the medical complaints of Black people seriously.	1	2	3	4	5
10.	Black people are treated the same as people of other groups by doctors and health care workers.	1	2	3	4	5
11.	In most hospitals, people of different racial and ethnic groups receive the same kind of care.	1	2	3	4	5
12.	I have personally been treated poorly or unfairly by doctors or health care workers because of my ethnicity.	1	2	3	4	5

### Section 11

Please read the following statements. Think about how much you agree or disagree with each statement and circle the number that best matches your opinion.

		Strongly disagree	Disagree	Agree	Strongly agree
1.	Overall, being Black has very little to do with how I feel about myself.	1	2	3	4
2.	In general, being Black is an important part of my self-image.	1	2	3	4
3.	My destiny is tied to the destiny of other Black people.	1	2	3	4
4.	Being Black is unimportant to my sense of what kind of person I am.	1	2	3	4
5.	I have a strong sense of belonging to Black people.	1	2	3	4
6.	I have a strong attachment to other Black people.	1	2	3	4
7.	Being Black is an important reflection of who I am.	1	2	3	4
8.	Being Black is not a major factor in my social relationships.	1	2	3	4

### Section 12

Below is a list of words that describe feelings people have. Please read each one carefully. Then circle the number which best describes HOW YOU HAVE BEEN FEELING DURING THE PAST WEEK INCLUDING TODAY. The numbers refer to the following descriptive phrases.

**0 = Not at all**  
**1 = A little**  
**2 = Moderately**  
**3 = Quite a bit**  
**4 = Extremely**

		Not at all	A little	Moderately	Quite a bit	Extremely
1.	Tense	0	1	2	3	4
2.	Unhappy	0	1	2	3	4
3.	Sorry	0	1	2	3	4
4.	Shaky	0	1	2	3	4
5.	Sad	0	1	2	3	4
6.	On edge	0	1	2	3	4
7.	Blue	0	1	2	3	4
8.	Panicky	0	1	2	3	4
9.	Hopeless	0	1	2	3	4
10.	Relaxed	0	1	2	3	4

11.	Unworthy	0	1	2	3	4
12.	Uneasy	0	1	2	3	4
13.	Restless	0	1	2	3	4
14.	Discouraged	0	1	2	3	4
15.	Nervous	0	1	2	3	4
16.	Lonely	0	1	2	3	4
17.	Miserable	0	1	2	3	4
18.	Anxious	0	1	2	3	4
19.	Gloomy	0	1	2	3	4
20.	Desperate	0	1	2	3	4
21.	Helpless	0	1	2	3	4
22.	Worthless	0	1	2	3	4
23.	Terrified	0	1	2	3	4
24.	Guilty	0	1	2	3	4

### Section 13

Think about how much you agree or disagree with each of the following statements. Select the number that best matches how much you agree or disagree with each statement.

		Strongly Disagree	Disagree	Undecided/ Neither agree nor disagree	Agree	Strongly Agree
1.	When I'm sick, I try to cure myself rather than go to the doctor.	1	2	3	4	5
2.	I rely more on home remedies than on doctors.	1	2	3	4	5
3.	If I feel healthy, I do not go to the doctor for a routine check-up.	1	2	3	4	5
4.	I keep a record so that I know when to schedule my next doctor's appointment.	1	2	3	4	5

## Section 14

Think about how much you agree or disagree with each of the following statements. Please indicate how much you agree or disagree with the following statements using the key below

Choose the number that best matches your agreement with each statement.

		Strongly disagree	Disagree	Agree	Strongly agree
1.	I am able to get medical care whenever I need it.	1	2	3	4
2.	Sometimes it is a problem to cover my share of the cost for a medical visit.	1	2	3	4
3.	Sometimes I go without the medical care I need because it is too expensive.	1	2	3	4
4.	Places where I can get medical care are conveniently located.	1	2	3	4
5.	If I have a medical question, I can reach a doctor or nurse for help.	1	2	3	4
6.	Health care providers often don't listen to people.	1	2	3	4
7.	I have easy access to the medical specialists I need.	1	2	3	4
8.	I don't worry much about the cost when I know I need to seek medical care.	1	2	3	4
9.	I see a different health care provider almost every time I go to an appointment.	1	2	3	4
10.	Money is an issue to me when I need to see the doctor.	1	2	3	4

## Section 15

In your opinion, how important is it that you and your family...

		Not at all important	Unimportant	Important	Very Important
1.	Let relatives stay with you for a short time when they need some help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Turn to each other in times of trouble	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Raise each other's children whenever there is a need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Do everything you can to help each other move ahead in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	Take responsibility for caring for older family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Call, write, or see each other often	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## **Appendix 4: Study introduction letter from Dr. Hall**

Date

«CompleteAddress»

Dear «Salutation» «LastName»,

We would like to invite you to participate in a focus group research study that will help us develop a brochure describing prostate cancer screening.

A focus group is a group discussion where 8-10 people come together to share their thoughts, feeling, and ideas about a particular topic. In the focus groups we are conducting, we will be asking about the attitudes of African American/ Black men toward health, cancer, and prostate cancer screening. This information will help us to develop more informative and effective brochures.

The focus group we are inviting you to will be conducted by a trained person, will be held at Mount Sinai, and will take about two hours. You will be paid \$75 for your time. A light dinner will be served. We can also reimburse you for travel.

Either I or my research coordinator will be contacting you soon to let you know when we will be conducting the focus groups. You may ask more questions about the focus groups or the research study in general at that time. We would greatly appreciate your participation and hope that you will join us.

Sincerely,

Simon J. Hall, MD  
Assistant Professor, Department of Urology  
Director, Maurice and Barbara Deane Prostate  
Health and Research Center

## **APPENDIX 5: Focus group questionnaire and moderator guides**

**Focus Group 1A Assessment:** Culturally Targeted Newsletter Draft, AA men age 45 and older who have never been diagnosed with prostate cancer and have had a PSA & DRE within the past 2 years.

1. What is your date of birth? \_\_\_\_/\_\_\_\_/\_\_\_\_ What is your age? \_\_\_\_\_ years of age

2. What is your marital status?

- ☐ Currently married
- ☐ Currently living with partner
- ☐ Separated
- ☐ Divorced
- ☐ Widowed
- ☐ Never married

3. Do you have any children? ☐ Yes ☐ No If yes, how many? \_\_\_\_\_

4. Are you currently employed? ☐ Yes ☐ No

5. What is the highest level of education that you completed?

- ☐ Less than 8<sup>th</sup> grade
- ☐ 8<sup>th</sup> to 11<sup>th</sup> grades
- ☐ High School graduate
- ☐ Some college or university
- ☐ Vocational or technical school
- ☐ Bachelor's Degree
- ☐ Graduate Degree

6. What is the estimated total income for your household for the past year, before taxes, from all sources?

- ☐ Less than \$10,000
- ☐ \$10,000 to \$19,999
- ☐ \$20,000 to \$39,999
- ☐ \$40,000 to \$59,999
- ☐ \$60,000 to \$100,000
- ☐ More than \$100,000

7. How many people are supported by this income? \_\_\_\_\_

8. Which of the following best describes you? Choose as many that apply.

- ☐ Black-American/African American
- ☐ Afro-Caribbean/West Indian

Which ethnic group (i.e. Jamaican, Guyanese)? \_\_\_\_\_

☐ African

Which ethnic group (i.e. Igbo, Yoruba)? \_\_\_\_\_

☐ Afro-Latino

Which group (i.e., Puerto Rican, Dominican)? \_\_\_\_\_

☐ Other \_\_\_\_\_

9. In which country were you born? (Please indicate which state if born in US.) \_\_\_\_\_

10. How many years have you lived in the US? \_\_\_\_\_ years \_\_\_\_\_ months

11. What type of health insurance do you have? Choose as many that apply.

- ☐ Medicaid
- ☐ Medicare
- ☐ Employer-provided insurance (like Oxford, Blue Cross/Blue Shield, HIP)
- ☐ Pay for insurance out-of-pocket
- ☐ I do not have health insurance (pay out of pocket for health care)
- ☐ Other \_\_\_\_\_
- ☐ I'm not sure

12. A primary care doctor is doctor who is trained to give you basic care. Your primary care doctor is the doctor you see first for most health problems. He or she makes sure that you get the care that you need to keep you healthy. He or she also may talk with other doctors and health care providers about your care and refer you to them. A primary care doctor is often a family doctor or internist.



Do you have a regular primary care doctor who you usually go to when you are sick or need healthcare?

☐ Yes ☐ No

What is that doctor's gender? ☐ Male ☐ Female Estimated ethnicity/race \_\_\_\_\_

13. When was your last visit to your primary care doctor?

- ☐ Within the past year
- ☐ 1 - 2 years ago
- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I don't have a regular primary care doctor

14. When was your last visit to any doctor?

- ☐ Within the past year
- ☐ 1 - 2 years ago
- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I don't have a regular primary care doctor

15. When should African American/Black men start being tested screened for prostate cancer screening?

- ☐ 35 years old
- ☐ 45 years old
- ☐ 55 years old
- ☐ 65 years old
- ☐ I'm not sure

16. How often should men been screened for prostate cancer

- ☐ Twice a year
- ☐ Once a year
- ☐ Once every 2 years
- ☐ Once every 5 years
- ☐ I'm not sure

17. How much have you heard or read about controversies or problems with prostate cancer screening?

- ☐ A lot
- ☐ A fair amount
- ☐ Relatively little
- ☐ Almost nothing

The following questions are about the PSA test (prostate specific antigen test). During a PSA test, a doctor or health care provider takes your blood to test for prostate cancer.

18. Has a doctor ever explained a PSA test to you?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

19. Has a doctor ever recommended that you have a PSA test?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

20. Have you ever had a PSA test?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

21. What was the date of your last PSA test?

- ☐ Within the past year

Date \_\_\_\_\_

- ☐ 1 - 2 years ago
- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I've never had this exam

22. Have the results of one of your PSA tests ever been abnormal?

- ☐ Yes
- ☐ No
- ☐ I'm not sure
- ☐ I've never had this exam

23. How reliable do you believe a PSA test is?

- ☐ Very reliable
- ☐ Somewhat reliable
- ☐ A little reliable
- ☐ Not at all reliable

The following questions are about digital rectal exam. During a digital rectal exam a doctor or health care provider inserts his or her finger in your rectum (your bottom) to check for prostate cancer.

24. Has a doctor ever explained a digital rectal exam to you?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

25. Has a doctor ever recommended that you have a digital rectal exam?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

26. Have you ever had a digital rectal exam?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

27. What was the date of your last digital rectal exam? Date \_\_\_\_\_

- ☐ Within the past year
- ☐ 1 - 2 years ago
- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I've never had this exam

28. Have the results of one of your digital rectal exams ever been abnormal?

- ☐ Yes
- ☐ No
- ☐ I'm not sure
- ☐ I've never had this exam

29. How reliable do you believe a digital rectal exam is?

- ☐ Very reliable
- ☐ Somewhat reliable
- ☐ A little reliable
- ☐ Not at all reliable

30. Have you ever had a biopsy (a surgery to diagnose cancer)?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

31. Do you have any blood relatives who have been diagnosed with prostate cancer?

- ☐ Yes  
☐ No  
☐ I'm not sure

If yes, please tell us which relatives.

- a. Father ☐ Yes ☐ No
- b. Grandfather (s) ☐ Yes ☐ No How many? \_\_\_\_\_
- c. Brother(s) ☐ Yes ☐ No How many? \_\_\_\_\_
- d. Son(s) ☐ Yes ☐ No How many? \_\_\_\_\_
- e. Uncles(s) ☐ Yes ☐ No How many? \_\_\_\_\_
- f. Nephew(s) ☐ Yes ☐ No How many? \_\_\_\_\_
- g. Cousin(s) ☐ Yes ☐ No How many? \_\_\_\_\_

32. Compared to other Black men, what do you think are your chances of getting prostate cancer?

- ☐ Much lower than others  
☐ Lower than others  
☐ About the same as others  
☐ Higher than others  
☐ Much higher than others

33. During the past two weeks...

a. How often have you worried about the possibility of getting prostate cancer?

- ☐ \_None of the time ☐ Occasionally ☐ Often ☐ All the time

b. How often has your mood been affected by your concern that you might get prostate cancer some day?

- ☐ \_None of the time ☐ Occasionally ☐ Often ☐ All the time

c. How emotionally upset or distressed have you been about the possibility of getting prostate cancer?

- ☐ None of the time ☐ Occasionally ☐ Often ☐ All the time

d. How often have thoughts about getting prostate cancer affected your ability to perform your daily activities?

- ☐ \_None of the time ☐ Occasionally ☐ Often ☐ All the time

How much do you agree with the following statements?

34. Overall, I am satisfied with my medical care.

- ☐ Strongly Agree ☐ Moderately Agree ☐ Not sure ☐ Moderately Disagree ☐ Strongly Disagree

35. I have a strong sense of belonging to Black people.

- ☐ Strongly Agree ☐ Moderately Agree ☐ Not sure ☐ Moderately Disagree ☐ Strongly Disagree

36. Have you ever been screened for colon cancer?

- ☐ Yes  
☐ No  
☐ I'm not sure

37. Have you ever been screened for high blood pressure?

- ☐ Yes  
☐ No  
☐ I'm not sure

38. Have you ever been screened for diabetes?

- ☐ Yes  
☐ No  
☐ I'm not sure

**Focus Group 1A Moderator Guide – Time1: AA men age 45 and older who have never been diagnosed with prostate cancer and have had a PSA & DRE within the past 2 years**

I. Moderator introduction

1. At this time, what kind of information do you have about prostate cancer?
2. Where did you get your information about prostate cancer?
  - a. Probes
    - i. From doctor, brochures, internet, video, spouse, family member, friend, church

II. Review of EHPCA prostate cancer education Powerpoint presentation (led by Simon Hall, MD)

3. Have you been screened for prostate cancer?
  - a. Probe
    - i. When was the last time you were screened?
    - ii. What did tests did you have?
4. What made you go for prostate cancer screening?
  - a. Probes (following each probe: How important is this issue for Black men in general?)
    - i. How did the each of the following influence your decision:
      1. Concern about health/desire to maintain good health
      2. Peace of mind
      3. Family
        - a. Do you have family members diagnosed with prostate cancer, have you talked to family about screening, do you have family members who have been screened, does your role in your family affect your decision to be screened
      4. Friends
        - a. Do you have friends who have been screened, have you talked to friends about screening?
      5. Physician recommendation, encouragement
        - a. What did physician tell you?
      6. Religious/spiritual values
        - a. Do you feel that it is God's will that you take care of your health?
5. Are there other things that may be important to Black men in general in making the decision to be screened for prostate cancer?
6. What do you think keeps Black men from getting screened?
  - a. Probes
    1. Limited information about prostate cancer
    2. Concerns that screening is uncomfortable or painful
    3. Concerns that screening is embarrassing or will make you feel like less of a man
    4. Fear
      - a. Are you worried that you might find out you have prostate cancer, if you learned you had cancer, how would your life change
      - b. Concerned that screening would add more stress to your life?
    5. Concerns about the side effects of treatment
    6. Stigma
      - a. If you learned you had cancer, how would it affect the way you would feel about yourself and view yourself, how others would view you?
    7. Belief that your risk of getting prostate cancer is low
    8. Mistrust of doctors and hospitals
      - a. How much do you trust PSA (the procedure, the results, etc.)? How much do you trust DRE?
    9. Fatalism
      - a. How much do you feel that there is nothing you can really do about cancer?
    10. Religious/spiritual values
      - a. Do you feel that if you get prostate cancer, it's God's will?
      - b. Do you leave your health in God's hands and not worry about prostate cancer?
    11. Medical costs and access
7. Are there other things that may keep Black men from being screened for prostate cancer?

8. [After moderator summarizes motivators of screening] How should a brochure for Black men address these issues?
9. [After moderator summarizes barriers to screening] How should a brochure for Black men address these issues?
10. [Comparison of standard and CT brochure via Powerpoint] What do you like or dislike about these brochures?
  - a. Probes
    - i. What do you think about the colors?
    - ii. What do you think about the graphics?
    - iii. What do you think about the topics covered?
    - iv. What do you think about the language used?
    - v. What do you think about the typeface?

Focus Group 1A Moderator Guide – Time2: AA men age 45 and older who have never been diagnosed with prostate cancer and have had a PSA & DRE within the past 2 years

1. [Review of CT brochure via Powerpoint and review of hard copy ] What do you like or dislike about the brochure?
  - a. Probes
    - i. What do you think about the colors?
    - ii. What do you think about the graphics?
    - iii. What do you think about the topics covered?
    - iv. What do you think about the language used?
    - v. What do you think about the typeface?

**Focus Group 1B Assessment: Culturally Targeted Newsletter Draft, AA men age 45 and older who have never been diagnosed with prostate cancer and have not had either a PSA or DRE in 2 years or more.**

1. What is your date of birth? \_\_\_\_/\_\_\_\_/\_\_\_\_ What is your age? \_\_\_\_\_ years of age

2. What is your marital status?

- ☐ Currently married  
☐ Currently living with partner  
☐ Separated  
☐ Divorced  
☐ Widowed  
☐ Never married

3. Do you have any children? ☐ Yes ☐ No If yes, how many? \_\_\_\_\_

4. Are you currently employed? ☐ Yes ☐ No

5. What is the highest level of education that you completed?

- ☐ Less than 8<sup>th</sup> grade  
☐ 8<sup>th</sup> to 11<sup>th</sup> grades  
☐ High School graduate  
☐ Some college or university  
☐ Vocational or technical school  
☐ Bachelor's Degree  
☐ Graduate Degree

12. What is the estimated total income for your household for the past year, before taxes, from all sources?

- ☐ Less than \$10,000  
☐ \$10,000 to \$19,999  
☐ \$20,000 to \$39,999  
☐ \$40,000 to \$59,999  
☐ \$60,000 to \$100,000  
☐ More than \$100,000

13. How many people are supported by this income? \_\_\_\_\_

14. Which of the following best describes you? Choose as many that apply.

- ☐ Black-American/African American  
☐ Afro-Caribbean/West Indian

Which ethnic group (i.e. Jamaican, Guyanese)? \_\_\_\_\_

- ☐ African

- Which ethnic group (i.e. Igbo, Yoruba)? \_\_\_\_\_
- ☐ Afro-Latino
- Which group (i.e., Puerto Rican, Dominican)? \_\_\_\_\_
- ☐ Other \_\_\_\_\_

15. In which country were you born?  
(Please indicate which state if born in US.) \_\_\_\_\_

16. How many years have you lived in the US? \_\_\_\_\_ years \_\_\_\_\_ months

17. What type of health insurance do you have? Choose as many that apply.

- ☐ Medicaid
- ☐ Medicare
- ☐ Employer-provided insurance (like Oxford, Blue Cross/Blue Shield, HIP)
- ☐ Pay for insurance out-of-pocket
- ☐ I do not have health insurance (pay out of pocket for health care)
- ☐ Other \_\_\_\_\_
- ☐ I'm not sure

12. A primary care doctor is doctor who is trained to give you basic care. Your primary care doctor is the doctor you see first for most health problems. He or she makes sure that you get the care that you need to keep you healthy. He or she also may talk with other doctors and health care providers about your care and refer you to them. A primary care doctor is often a family doctor or internist.

Do you have a regular primary care doctor who you usually go to when you are sick or need healthcare?

- ☐ Yes ☐ No

What is that doctor's gender? ☐ Male ☐ Female Estimated ethnicity/race \_\_\_\_\_

13. When was your last visit to your primary care doctor?

- ☐ Within the past year
- ☐ 1 - 2 years ago
- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I don't have a regular primary care doctor

14. When was your last visit to any doctor?

- ☐ Within the past year
- ☐ 1 - 2 years ago
- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I don't have a regular primary care doctor

15. When should African American/Black men start being tested screened for prostate cancer screening?

- ☐ 35 years old
- ☐ 45 years old
- ☐ 55 years old
- ☐ 65 years old
- ☐ I'm not sure

16. How often should men been screened for prostate cancer

- ☐ Twice a year
- ☐ Once a year
- ☐ Once every 2 years
- ☐ Once every 5 years
- ☐ I'm not sure

17. How much have you heard or read about controversies or problems with prostate cancer screening?

- ☐ A lot
- ☐ A fair amount

- ☐ Relatively little
- ☐ Almost nothing

**The following questions are about the PSA test (prostate specific antigen test). During a PSA test, a doctor or health care provider takes your blood to test for prostate cancer.**

18. Has a doctor ever explained a PSA test to you?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

19. Has a doctor ever recommended that you have a PSA test?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

20. Have you ever had a PSA test?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

21. What was the date of your last PSA test?

**Date** \_\_\_\_\_

- ☐ Within the past year
- ☐ 1 - 2 years ago
- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I've never had this exam

22. Have the results of one of your PSA tests ever been abnormal?

- ☐ Yes
- ☐ No
- ☐ I'm not sure
- ☐ I've never had this exam

23. How reliable do you believe a PSA test is?

- ☐ Very reliable
- ☐ Somewhat reliable
- ☐ A little reliable
- ☐ Not at all reliable

**The following questions are about digital rectal exam. During a digital rectal exam a doctor or health care provider inserts his or her finger in your rectum (your bottom) to check for prostate cancer.**

24. Has a doctor ever explained a digital rectal exam to you?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

25. Has a doctor ever recommended that you have a digital rectal exam?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

26. Have you ever had a digital rectal exam?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

27. What was the date of your last digital rectal exam? **Date** \_\_\_\_\_

- ☐ Within the past year
- ☐ 1 - 2 years ago

- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I've never had this exam

28. Have the results of one of your digital rectal exams ever been abnormal?

- ☐ Yes
- ☐ No
- ☐ I'm not sure
- ☐ I've never had this exam

29. How reliable do you believe a digital rectal exam is?

- ☐ Very reliable
- ☐ Somewhat reliable
- ☐ A little reliable
- ☐ Not at all reliable

28. Have you ever had a biopsy (a surgery to diagnose cancer)?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

29. Do you have any blood relatives who have been diagnosed with prostate cancer?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

If yes, please tell us which relatives.

- |                    |                              |                             |                 |
|--------------------|------------------------------|-----------------------------|-----------------|
| a. Father          | <input type="checkbox"/> Yes | <input type="checkbox"/> No |                 |
| b. Grandfather (s) | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |
| c. Brother(s)      | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |
| d. Son(s)          | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |
| e. Uncles(s)       | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |
| f. Nephew(s)       | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |
| g. Cousin(s)       | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |

30. Compared to other Black men, what do you think are your chances of getting prostate cancer?

- ☐ Much lower than others
- ☐ Lower than others
- ☐ About the same as others
- ☐ Higher than others
- ☐ Much higher than others

31. During the past **two weeks**...

- a. How often have you worried about the possibility of getting prostate cancer?  
☐ \_None of the time    ☐ Occasionally    ☐ Often    ☐ All the time
- b. How often has your mood been affected by your concern that you might get prostate cancer some day?  
☐ \_None of the time    ☐ Occasionally    ☐ Often    ☐ All the time
- c. How emotionally upset or distressed have you been about the possibility of getting prostate cancer?  
☐ None of the time    ☐ Occasionally    ☐ Often    ☐ All the time
- d. How often have thoughts about getting prostate cancer affected your ability to perform your daily activities?  
☐ \_None of the time    ☐ Occasionally    ☐ Often    ☐ All the time



**How much do you agree with the following statements?**

32. Overall, I am satisfied with my medical care.  
☐ Strongly Agree    ☐ Moderately Agree    ☐ Not sure    ☐ Moderately Disagree    ☐ Strongly Disagree
33. I have a strong sense of belonging to Black people.  
☐ Strongly Agree    ☐ Moderately Agree    ☐ Not sure    ☐ Moderately Disagree    ☐ Strongly Disagree
34. Have you ever been screened for colon cancer?  
☐ Yes  
☐ No  
☐ I'm not sure
35. Have you ever been screened for high blood pressure?  
☐ Yes  
☐ No  
☐ I'm not sure
36. Have you ever been screened for diabetes?  
☐ Yes  
☐ No  
☐ I'm not sure

**Focus Group 1B Moderator Guide – Time1: Culturally Targeted Newsletter Draft, AA men age 45 and older who have never been diagnosed with prostate cancer and have not had either a PSA or DRE in 2 years or more.**

**III. Moderator introduction**

6. At this time, what kind of information do you have about prostate cancer?
7. Where did you get your information about prostate cancer?
- a. Probes
    - i. From doctor, brochures, internet, video, spouse, family member, friend, church

**IV. Review of EHPCA prostate cancer education Powerpoint presentation (led by Simon Hall, MD)**

8. Have you been screened for prostate cancer?
- a. Probe
    - i. When was the last time you were screened?
    - ii. What did tests did you have?
9. What has kept you from getting screened for prostate cancer?
- a. Probes (following each probe: How important is this issue for Black men in general?)
    - i. How did the each of the following influence your decision:
      - a. Limited information about prostate cancer
      - b. Concerns that screening is uncomfortable or painful
      - c. Concerns that screening is embarrassing or will make you feel like less of a man
      - d. Fear
        - i. Are you worried that you might find out you have prostate cancer, if you learned you had cancer, how would your life change
        - ii. Concerned that screening would add more stress to your life?
      - e. Concerns about the side effects of treatment
      - f. Stigma
        - i. If you learned you had cancer, how would it affect the way you would feel about yourself and view yourself, how others would view you?
      - g. Belief that your risk of getting prostate cancer is low
      - h. Mistrust of doctors and hospitals
        - i. How much do you trust PSA (the procedure, the results, etc.)? How much do you trust DRE?
      - i. Fatalism
        - i. How much do you feel that there is nothing you can really do about cancer?
      - j. Religious/spiritual values
        - i. Do you feel that if you get prostate cancer, it's God's will?
        - ii. Do you leave your health in God's hands and not worry about prostate cancer?
      - k. Medical costs and access
5. Are there other things that may keep Black men from being screened for prostate cancer?

6. What do you think makes Black men get screened for prostate cancer?
  - b. Probes
    - i. Concern about health/desire to maintain good health
    - ii. Peace of mind
    - iii. Family
      1. Do you have family members diagnosed with prostate cancer, have you talked to family about screening, do you have family members who have been screened, does your role in your family affect your decision to be screened
    - iv. Friends
      1. Do you have friends who have been screened, have you talked to friends about screening?
    - v. Physician recommendation, encouragement
      1. What did physician tell you?
    - vi. Religious/spiritual values
      1. Do you feel that it is God's will that you take care of your health?
11. Are there other things that may be important to Black men that makes them go for prostate cancer screening?
12. [After moderator summarizes barriers to screening] How should a brochure for Black men address these issues?
13. [After moderator summarizes motivators of screening] How should a brochure for Black men address these issues?
14. [Comparison of standard and CT brochure via Powerpoint] What do you like or dislike about these brochures?
  - a. Probes
    - i. What do you think about the colors?
    - ii. What do you think about the graphics?
    - iii. What do you think about the topics covered?
    - iv. What do you think about the language used?
    - v. What do you think about the typeface?

**Focus Group 1B Moderator Guide – Time2: Culturally Targeted Newsletter Draft, AA men age 45 and older who have never been diagnosed with prostate cancer and have not had either a PSA or DRE in 2 years or more.**

1. [Review of CT brochure via Powerpoint and review of hard copy ] What do you like or dislike about the brochure?
  - a. Probes
    - i. What do you think about the colors?
    - ii. What do you think about the graphics?
    - iii. What do you think about the topics covered?
    - iv. What do you think about the language used?
    - v. What do you think about the typeface?

**Focus Group 1C Assessment: Culturally Targeted Newsletter Draft, AA prostate cancer survivors, age 45 and older.**

1. What is your date of birth? \_\_\_\_/\_\_\_\_/\_\_\_\_ What is your age? \_\_\_\_\_ years of age
2. What is your marital status?
  - ☐ Currently married
  - ☐ Currently living with partner
  - ☐ Separated
  - ☐ Divorced
  - ☐ Widowed
  - ☐ Never married
3. Do you have any children? ☐Yes ☐No If yes, how many? \_\_\_\_\_
18. Are you currently employed? ☐Yes ☐No
19. What is the highest level of education that you completed?
  - ☐ Less than 8<sup>th</sup> grade
  - ☐ 8<sup>th</sup> to 11<sup>th</sup> grades
  - ☐ High School graduate
  - ☐ Some college or university
  - ☐ Vocational or technical school
  - ☐ Bachelor's Degree
  - ☐ Graduate Degree
20. What is the estimated total income for your household for the past year, before taxes, from all sources?
  - ☐ Less than \$10,000

- ☐ \$10,000 to \$19,999
- ☐ \$20,000 to \$39,999
- ☐ \$40,000 to \$59,999
- ☐ \$60,000 to \$100,000
- ☐ More than \$100,000

21. How many people are supported by this income? \_\_\_\_\_

22. Which of the following best describes you? Choose as many that apply.

- ☐ Black-American/African American
- ☐ Afro-Caribbean/West Indian Which ethnic group (i.e. Jamaican, Guyanese)? \_\_\_\_\_
- ☐ African Which ethnic group (i.e. Igbo, Yoruba)? \_\_\_\_\_
- ☐ Afro-Latino Which group (i.e., Puerto Rican, Dominican)? \_\_\_\_\_
- ☐ Other \_\_\_\_\_

23. In which country were you born?

(Please indicate which state if born in US.) \_\_\_\_\_

24. How many years have you lived in the US? \_\_\_\_\_ years \_\_\_\_\_ months

25. What type of health insurance do you have? Choose as many that apply.

- ☐ Medicaid
- ☐ Medicare
- ☐ Employer-provided insurance (like Oxford, Blue Cross/Blue Shield, HIP)
- ☐ Pay for insurance out-of-pocket
- ☐ I do not have health insurance (pay out of pocket for health care)
- ☐ Other \_\_\_\_\_
- ☐ I'm not sure

12. A primary care doctor is doctor who is trained to give you basic care. Your primary care doctor is the doctor you see first for most health problems. He or she makes sure that you get the care that you need to keep you healthy. He or she also may talk with other doctors and health care providers about your care and refer you to them. A primary care doctor is often a family doctor or internist.

Do you have a regular primary care doctor who you usually go to when you are sick or need healthcare?

- ☐ Yes
- ☐ No

What is that doctor's gender? ☐ Male ☐ Female Estimated ethnicity/race \_\_\_\_\_

13. When was your last visit to your primary care doctor?

- ☐ Within the past year
- ☐ 1 - 2 years ago
- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I don't have a regular primary care doctor

14. When was your last visit to any doctor?

- ☐ Within the past year
- ☐ 1 - 2 years ago
- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I don't have a regular primary care doctor

15. When should African American/Black men start being tested screened for prostate cancer screening?

- ☐ 35 years old
- ☐ 45 years old
- ☐ 55 years old
- ☐ 65 years old
- ☐ I'm not sure

16. How often should men been screened for prostate cancer

- ☐ Twice a year
- ☐ Once a year
- ☐ Once every 2 years
- ☐ Once every 5 years
- ☐ I'm not sure

17. When were you diagnosed with prostate cancer? Date \_\_\_\_\_

18. What was the stage of your prostate cancer when you were diagnosed? \_\_\_\_\_

19. What treatment did you receive for your prostate cancer?

- ☐ Watchful waiting
- ☐ Surgery
- ☐ External beam radiation therapy
- ☐ Brachytherapy (seed implants)
- ☐ Hormone therapy

20. How much have you heard or read about controversies or problems with prostate cancer screening?

- ☐ A lot
- ☐ A fair amount
- ☐ Relatively little
- ☐ Almost nothing

**The following questions are about the PSA test (prostate specific antigen test). During a PSA test, a doctor or health care provider takes your blood to test for prostate cancer.**

21. Has a doctor ever explained a PSA test to you?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

22. Has a doctor ever recommended that you have a PSA test?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

23. Have you ever had a PSA test?

- ☐ Yes
- ☐ No
- ☐ I'm not sure

24. What was the date of your last PSA test? **Date** \_\_\_\_\_

- ☐ Within the past year
- ☐ 1 - 2 years ago
- ☐ 2 - 3 years ago
- ☐ 3 - 5 years ago
- ☐ More than 5 years ago
- ☐ I'm not sure
- ☐ I've never had this exam

25. Have the results of one of your PSA tests ever been abnormal?

- ☐ Yes
- ☐ No
- ☐ I'm not sure
- ☐ I've never had this exam

26. How reliable do you believe a PSA test is?

- ☐ Very reliable
- ☐ Somewhat reliable
- ☐ A little reliable
- ☐ Not at all reliable

**The following questions are about digital rectal exam. During a digital rectal exam a doctor or health care provider inserts his or her finger in your rectum (your bottom) to check for prostate cancer.**

27. Has a doctor ever explained a digital rectal exam to you?

- ☐ Yes  
☐ No  
☐ I'm not sure

28. Has a doctor ever recommended that you have a digital rectal exam?

- ☐ Yes  
☐ No  
☐ I'm not sure

29. Have you ever had a digital rectal exam?

- ☐ Yes  
☐ No  
☐ I'm not sure

30. What was the date of your last digital rectal exam? **Date** \_\_\_\_\_

- ☐ Within the past year  
☐ 1 - 2 years ago  
☐ 2 - 3 years ago  
☐ 3 - 5 years ago  
☐ More than 5 years ago  
☐ I'm not sure  
☐ I've never had this exam

31. Have the results of one of your digital rectal exams ever been abnormal?

- ☐ Yes  
☐ No  
☐ I'm not sure  
☐ I've never had this exam

32. How reliable do you believe a digital rectal exam is?

- ☐ Very reliable  
☐ Somewhat reliable  
☐ A little reliable  
☐ Not at all reliable

33. Have you ever had a biopsy (a surgery to diagnose cancer)?

- ☐ Yes  
☐ No  
☐ I'm not sure

34. Do you have any blood relatives who have been diagnosed with prostate cancer?

- ☐ Yes  
☐ No  
☐ I'm not sure

If yes, please tell us which relatives.

- |                    |                              |                             |                 |
|--------------------|------------------------------|-----------------------------|-----------------|
| a. Father          | <input type="checkbox"/> Yes | <input type="checkbox"/> No |                 |
| b. Grandfather (s) | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |
| c. Brother(s)      | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |
| d. Son(s)          | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |
| e. Uncles(s)       | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |
| f. Nephew(s)       | <input type="checkbox"/> Yes | <input type="checkbox"/> No | How many? _____ |

g. Cousin(s) ☐ Yes ☐ No How many? \_\_\_\_\_

35. During the past **two weeks**...

- a. How often have you worried about the possibility of getting prostate cancer again?  
☐ None of the time ☐ Occasionally ☐ Often ☐ All the time
- b. How often has your mood been affected by your concern that you might get prostate cancer again?  
☐ None of the time ☐ Occasionally ☐ Often ☐ All the time
- c. How emotionally upset or distressed have you been about the possibility of getting prostate cancer again?  
☐ None of the time ☐ Occasionally ☐ Often ☐ All the time
- d. How often have thoughts about getting prostate cancer again affected your ability to perform your daily activities?  
☐ None of the time ☐ Occasionally ☐ Often ☐ All the time

**How much do you agree with the following statements?**

36. Overall, I am satisfied with my medical care.  
☐ Strongly Agree ☐ Moderately Agree ☐ Not sure ☐ Moderately Disagree ☐ Strongly Disagree

38. I have a strong sense of belonging to Black people.  
☐ Strongly Agree ☐ Moderately Agree ☐ Not sure ☐ Moderately Disagree ☐ Strongly Disagree

39. Have you ever been screened for colon cancer?

- ☐ Yes  
☐ No  
☐ I'm not sure

40. Have you ever been screened for high blood pressure?

- ☐ Yes  
☐ No  
☐ I'm not sure

41. Have you ever been screened for diabetes?

- ☐ Yes  
☐ No  
☐ I'm not sure

**Focus Group 1C Moderator Guide- Time 1: AA prostate cancer survivors, age 45 and older.**

**V. Moderator introduction**

1. How did you learn about your prostate cancer?
2. How was your prostate cancer treated?
3. At this time, what kind of information do you have about prostate cancer?
4. Where did you get your information about prostate cancer?
  - a. Probes
    - i. From doctor, brochures, internet, video, spouse, family member, friend, church
5. Before you were diagnosed with prostate cancer, did you go for regular prostate cancer screening?
  - a. Probe
    - i. When was the last time you were screened?
6. If you were screened regularly for prostate cancer before your diagnosis, what made you go?
  - a. Probes (following each probe: How important is this issue for Black men in general?)
    - i. How did each of the following influence your decision:
      1. Concern about health/desire to maintain good health
      2. Peace of mind
      3. Family
        - a. Do you have family members diagnosed with prostate cancer, have you talked to family about screening, do you have family members who have been screened, does your role in your family affect your decision to be screened
      4. Friends

- a. Do you have friends who have been screened, have you talked to friends about screening?
    - 5. Physician recommendation, encouragement
      - a. What did physician tell you?
    - 6. Religious/spiritual values
      - a. Do you feel that it is God's will that you take care of your health?
  - 7. Are there other things that may be important to Black men in general in making the decision to be screened for prostate cancer?
  - 8. If you had not been screened or put off screening before your prostate cancer diagnosis, what kept you from going?
    - a. Probes (following each probe: How important is this issue for Black men in general?)
      - i. How did the each of the following influence your decision:
        - 1. Limited information about prostate cancer
        - 2. Concerns that screening is uncomfortable or painful
        - 3. Concerns that screening is embarrassing or will make you feel like less of a man
        - 4. Fear
          - b. Are you worried that you might find out you have prostate cancer, if you learned you had cancer, how would your life change
          - c. Concerned that screening would add more stress to your life?
        - 5. Concerns about the side effects of treatment
        - 6. Stigma
          - d. If you learned you had cancer, how would it affect the way you would feel about yourself and view yourself, how others would view you?
      - 7. Belief that your risk of getting prostate cancer is low
      - 8. Mistrust of doctors and hospitals
        - a. How much do you trust PSA (the procedure, the results, etc.)? How much do you trust DRE?
      - 9. Fatalism
        - a. How much do you feel that there is nothing you can really do about cancer?
      - 10. Religious/spiritual values
        - a. Do you feel that if you get prostate cancer, it's God's will?
        - b. Do you leave your health in God's hands and not worry about prostate cancer?
      - 11. Medical costs and access
9. Are there other things that may keep Black men from being screened for prostate cancer?
10. [After moderator summarizes motivators of screening] How should a brochure for Black men address these issues?
11. [After moderator summarizes barriers to screening] How should a brochure for Black men address these issues?
12. [Comparison of standard and CT brochure via Powerpoint] What do you like or dislike about these brochures?
  - b. Probes
    - i. What do you think about the colors?
    - ii. What do you think about the graphics?
    - iii. What do you think about the topics covered?
    - iv. What do you think about the language used?
    - v. What do you think about the typeface?

Focus Group 1C Moderator Guide- Time 1: AA prostate cancer survivors, age 45 and older.

- 1. [Review of CT brochure via Powerpoint and review of hard copy ] What do you like or dislike about the brochure?
  - a. Probes
    - i. What do you think about the colors?
    - ii. What do you think about the graphics?
    - iii. What do you think about the topics covered?
    - iv. What do you think about the language used?
    - v. What do you think about the typeface?